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**An investigation into the nature and content of spontaneous attributions and  
their relationship to feelings of self-efficacy and stress in parents of individuals  
with intellectual disabilities who exhibit self-injurious behaviour  
& research portfolio**

**PART ONE**

**(Part Two bound separately)**

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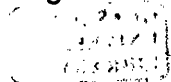
**Section of Psychological Medicine**

**Division of Community Based Sciences**

**Submitted in partial fulfilment of the requirements for the degree of Doctorate in**

**Clinical Psychology within the Faculty of Medicine, University of Glasgow**

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## **Chapter 1**

### **Small Scale Service-Related Project**

#### **Profile of Anger Management Cases in an Adult Mental Health Outpatient Clinic.**

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## **ABSTRACT**

### **OBJECTIVE**

Previous research has shown that there has been an escalation in the number of people referred for anger problems and that these patients often drop out of treatment. An audit was undertaken to determine whether such referrals had increased over the audit period and whether the drop out rate was high.

### **DESIGN**

A retrospective review of information contained in the departmental database, including age, gender, postcode (for socioeconomic status), source of referral, disposal code and outcome.

### **SETTING**

An Adult Mental Health outpatient department.

### **SUBJECTS**

Patients coded as having anger problems for whom data were available on the departmental database (N=268) for the audit period (1995-2003).

### **RESULTS**

Demographic information was investigated for potential indicators of treatment drop out. Results indicated that these cases do appear to be on the increase, and 70.8% of the cohort dropped out of treatment. Gender or social class did not predict treatment completion, although the unplanned discharge group was younger. Patients who dropped out of treatment attended fewer sessions and DNA'd more often. Whether referrals came from GPs or psychiatry did not affect attendance patterns to the service.

### **CONCLUSIONS**

Conclusions must be tentative due to data quality related to this type of retrospective review. However, demographic factors do not appear to predict who will stay in treatment and who will drop out and it may be the case that motivation and impediments to readiness may be more important variables. Guidance for referring

agents as to suitability may be effective in reducing drop out. In all, however, the high drop out rate compromises service provision and clinical efficacy.

## INTRODUCTION

Anger has been defined as a combination of physiological arousal and the subjective labelling of that arousal as anger or a semantic equivalent (Novaco 1978). Although anger has many positive functions it also has a number of less adaptive functions. Therefore anger per se is not a problem and has no specific diagnostic criteria itself, although it is a factor in several others, but becomes problematic when it leads to aggression, or impairs social relationships, physical or psychological health and adjustment (Novaco 1985). Anger-mediated aggression is frequently a factor in offences of violence. Serious violence tends to occur in a domestic context typically as a result of an angry dispute or disagreement. This is true for homicide (Home Office 1961; West 1965); child abuse (Frude 1989); spouse and elder abuse (Browne 1989) and for the violence directed at women by their male partners (Dobash & Dobash 1984).

Those referred with anger management problems are notoriously difficult to help, either individually or in therapy groups (O'Loughlin et al 2004). As Awenat et al (2002) state, anger problems can be debilitating for families and can result in psychological and physiological damage to victims of attacks made in anger. Furthermore, it has been linked to hypertension (Speilberger, 1979) and can significantly impair the ability to sustain relationships and stay in employment. There is little evidence to show that anger management problems improve of their own accord and given that there is a risk of future aggression, anger management is an important service to offer.

Cognitive behavioural therapy (CBT) has made significant and widely acknowledged progress as a method for reducing emotional distress of various sorts, even with complex and difficult clients (Tarrier, Wells & Haddock 1998). Interventions for anger problems, however, have been relatively neglected compared to those for other

emotional disorders (DiGiuseppe 1999). There is, however, some evidence that CBT can be an effective treatment for people with anger problems with little difference in effectiveness between group and individual treatment (Mayne & Ambrose 1999). However, offering treatment is only one aspect to consider. Client attendance is also an important consideration as time and resources are frequently wasted through non-attendance (Hird et al 1997, Awenat et al 2002).

Hird et al (1997) investigated factors predicting likelihood to attend treatment and found that clients are more likely to attend if they face consequences for not doing so. Furthermore, increasing age was also associated with attendance whereas source of referral and the presence of external motivating factors were not. A further study of factors differentiating between attenders and non-attenders for anger problems treatment (Awenat et al 2002) showed that people who attended for treatment regarded their anger as more severe than those who did not attend. Furthermore, at assessment therapists predicted more benefit from treatment for those who went on to attend than non-attenders. This was because they were judged to be more optimistic, more psychologically minded and to have an accurate assessment of their own problem.

As Howells and Day (2003) have stated, many emotions, such as anger, fear and sadness are not inherently problematic but become so because of their intensity, frequency, or most importantly their behavioural effects which may become a source of distress to themselves or others. The relative importance of distress to self and others to the process of help-seeking may vary for different emotions. Anxiety and depression are distressing states for the individual who is, therefore, often motivated to change their affective state. Anger is not necessarily problematic for the person. Thus it is hypothesised that help-seeking in relation to an anger problem will often be instigated by others, either directly or indirectly. Howells and Day purport that the

'readiness' of a client to undertake the therapeutic intervention may be a major impact on the effectiveness of treatments for anger problems.

The Psychology Department at Dykebar Hospital has traditionally received a steady stream of referrals for anger management, which eventually led to establishing groups specifically for anger management training. Anecdotally, in recent years this appears to have brought about an increase in referrals of this type as Dykebar came to be viewed as the appropriate place for people to be sent due to the fact that groups were run there. However, recently there have been difficulties with the groups as a lot of clinician time is spent in initially assessing/screening for groups only for the dropout rate to be subsequently so high that groups are no longer run. Currently, there are no anger management groups being run at Dykebar, although staff perception is that the number of referrals remains constant. The Department of Health (2003) has shown that nationally there has been an escalation in the proportion of people referred with anger problems, with a knock-on effect on waiting times. Thornhill (2000) has demonstrated that, within the service where the present study will be conducted, young males from a low socioeconomic background are more likely to drop out of treatment. This is an important issue as the common perception of anger management referrals is of "angry young men". One of the aims of this study is to establish whether this perception is correct.

The aim of this project was to gain a statistical profile of referrals for anger management, and to track their pathway through the service.

Specifically, the information gathered would include gaining a picture of the number of anger management referrals per annum and show whether or not they had increased over the audit period. Also, demographic information could show whether those patients who complete treatment were different to those that drop out and whether the source of referral made a difference to attendance.

## **METHODOLOGY**

The Psychology Department at Dykebar Hospital keeps a database of patients. The data for this audit are taken from a retrospective review of the database and data were obtained for the number of people coded as having anger problems, discharge codes, number of contacts with the service, source of referral, age, gender and postcode. The audit period covered 1995 to 2003 and included only those patients who had been discharged from the service.

The postcode data were used to obtain a deprivation score of 1 to 7 based on Carstairs scores for Scottish postcode sectors from the 2001 census obtained from a Glasgow University website. A score of 1 reflects the least deprivation and a score of 7 the most deprivation, with the UK average being 4. Carstairs scores were originally developed by Carstairs and Morris (1991) and are a summary measure of relative disadvantage between populations contained within small geographic localities.

## **RESULTS**

Data were obtained on 268 patients referred for anger problems who had been discharged. The relevant discharge codes consist of: unplanned discharge dropped out (UDDO), unplanned discharge refused appointment (UDRA) and unplanned discharge moved away (UDMA), making up an unplanned discharge category, and planned discharge therapy complete (PDTC), planned discharge therapy incomplete (PDTI), planned discharge assessment only (PDAO), and transferred, making up a planned discharge category. No discharge code was available for 8 patients and these were therefore excluded from further analysis. Unplanned discharges made up 70.8% (n=184) of the cohort for whom discharge data were available. A breakdown of the numbers of patients allocated to each discharge code is displayed in Table 1.

.....  
INSERT TABLE 1  
.....

The mean age of the total sample (268) was 31.6 (standard deviation 4.6, range 16-67). Males made up 82.1% of the sample (220) and females 17.9% (48). The median Carstairs deprivation score was 5.

The number of patients referred for anger problems over the audit period was a primary focus of the analysis. The number of referrals per annum and whether their discharge was planned or unplanned can be seen in Table 2 below.

.....  
INSERT TABLE 2  
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The number of referrals for anger problems does appear to have increased since 2001, reaching a peak of 73 in 2002, and unplanned discharges have remained consistently high.

An examination of the demographic data for the planned and unplanned discharge groups was undertaken in an attempt to discover whether these types of variables may be important in distinguishing between these groups. The mean age of the planned discharge group (n=76) was 35.4 (SD 10.5, range 17-67), with males making up 85.5% of the group (65) and females 14.5% (11). For the unplanned discharge group (n=184), the mean age was 29.0 (SD 10.0, range 16-66) and males made up 81.0% (149) and females 19.0% (35) of the group. The median Carstairs deprivation score for both groups was 5.

The two groups are very similar in their profiles with the majority of cases being males from low socio-economic backgrounds. However, the unplanned discharge group is significantly younger (t 4.06 (258), p=0.000).

The pattern of attendance to the service was investigated in order to determine whether this differed between the planned and unplanned discharge groups. The number of sessions attended, the number of sessions not attended by the patient, the source of referral and therapy outcome are displayed below for each group in Tables 3 to 6.

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INSERT TABLE 3  
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INSERT TABLE 4  
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Chi square analysis showed that the unplanned discharge group attended significantly fewer sessions and DNA significantly more sessions (number of sessions  $X^2(2)$  40.78, p=0.000; DNAs  $X^2(1)$  59.80, p=0.000). Whether referrals come from the GP or from psychiatry does not appear to affect the pattern of attendance to the service. The analysis for therapy outcome did not include “Assessment Only”



outcome codes. Those whose discharge from the service was planned tend to have better therapy outcomes ( $\chi^2(1) 11.08, p=0.001$ ). Cancellations were not investigated as they attended fewer sessions and did not attend for more sessions, they would have had less opportunity to cancel sessions.

## **DISCUSSION**

The results of this audit appear to support staff's view of the referrals for anger problems to the service being predominantly younger males. In general, these patients tend to come from a lower socioeconomic background, although this may reflect the service catchment area generally.

It does appear from the data that referrals for anger problems have been on the increase in recent years. The peak was 2002 for which data on 73 cases are available, although numbers have been on the increase since 2001. This may be due to referring agents becoming aware of anger management groups being run and affected the likelihood of referral. Although the most recent year of the audit period, 2003, showed only 44 people being referred with anger problems, it may be the case that not all the referrals made in this year have completed their contact with the service. Some of these patients may still be in treatment.

Factors such as gender and deprivation index do not appear to predict whether or not a patient will drop out of treatment, although age may be a factor as the unplanned discharge group is significantly younger, a finding supported by previous research (Thornhill 2000; Hird et al 1997). However, it does seem that a planned discharge is the exception rather than the rule, as 70.8% of patients drop out of contact with the service. This is compared to an average drop out rate of around 30% for adult clinical psychology services (Thornhill 2000). This therefore makes examination of the pattern of attendance to the service important, as previous research has shown

that early dropout often means that the patient exits the service at the assessment stage. This means that there has been no opportunity for specific treatment for the problem which leads to potential for re-referral to the service (Startup 1994). In a DCP review of waiting list for NHS clinical psychology services (DCP 1993), Adult Mental Health services had the highest percentage of total numbers waiting (67%). If these patients were to be re-referred, they will add pressure to already weighty waiting times and lead to the misuse of valuable clinician preparation and consultation time.

Those patients in the unplanned discharge group tend on average to attend for fewer sessions before exiting the service. The median number of sessions attended is one, and the majority drop out having attended for four sessions or less, thus dropping out of treatment early on. It is a drawback of this type of investigation based on a retrospective review of database information that the precise pattern of attendance cannot be determined. A pattern of attendance such as attending for a number of consecutive sessions and then dropping out because of perceived improvement would be interpreted quite differently from the patient who attends for one session, fails to attend for the next two, attends again, cancels the next and then drops out. However, from the data, it appears that in general, patients attend for a session and fail to engage and consequently drop out of treatment. A pattern such as this would chime with the findings of Howells and Day (2003) concerning the concept of 'readiness' in people with problem anger. They have identified a number of impediments to readiness to engage in treatment, including existing client inferences about their anger problem. DiGiuseppe (1995) identifies attitudes and beliefs in angry people that prevent them reaching an agreement with the therapist on treatment goals: anger is appropriate, low personal responsibility and other blame, victim condemnation, self-righteousness and the belief that anger works. Another impediment to treatment readiness occurs when a client believes that they have been

pressured into attending for treatment against their own wishes. Although this audit is unable to investigate factors such as these, they may be important in determining attendance to the service. It may be the case that referring agents should be instructed in how to make these judgements before making a referral to the service, or that these should be the focus of assessment before accepting the client for treatment, perhaps with reference to Prochaska and DiClemente's (1992) transtheoretical stages of change model. Any further investigation of referrals for anger management to Dykebar should address these issues.

Changing client readiness would involve modifying impediments to readiness prior to undertaking the anger management programme per se. These pre-treatment interventions may be along the lines of the Anger Management Fast-Track outlined by Munro and Macpherson (2001) with referrals screened for suitability and guidance to referring agents on inclusion and exclusion criteria. Howells and Day (2003) have also suggested that a greater focus on therapeutic engagement and a collaborative relationship may enhance readiness to engage in treatment and thus reduce drop out rates. Siddle et al. (2003) in their pilot of a group CBT intervention for anger problems reported that patients would have preferred a longer course of treatment than the six sessions offered. However, only 9% of those referred for therapy completed treatment. The problem then arises of balancing the fruitful use of therapy time between engaging the client and delivering effective interventions.

There is a caveat to this audit in that the database is based on discharge data and the referral problem is not recorded. This may mean that some patients referred with problem anger and who have no contact with the service at all are discharged without a problem being entered by the clinician and some relevant referrals may have been missed. Furthermore, some of the cases are re-referrals, but from the dates are treated as discrete episodes.

In conclusion then, the results of this audit suggest that referrals for anger problems to this service have increased since 2001 and although variable in number, remain high, and that over the audit period 70.8% of patients have dropped out of treatment. Demographic factors are not clear predictors of who will stay in treatment and who will drop out, although age appears to be a factor, and it may be the case that motivation and impediments to readiness may be more important variables. Pre-treatment interventions aimed at increasing readiness may be utilised in an attempt to ensure therapeutic engagement and completion. However, these will not affect those clients who are offered appointments and who never attend the service. It may be the case that guidance for referring agents as to suitability may be more effective. In all, however, the high drop out rate compromises service provision and clinical efficacy. Future research may include an investigation of motivational and readiness factors and pattern of attendance to the service, or an evaluation of any measures put in place to deal with the number of referrals and high unplanned discharge rate.

Table 1. Number of patients allocated to each disposal code (n=260)

<b>Code</b>	<b>Frequency</b>	<b>Valid % (missing cases removed)</b>
<b>UDDO</b>	129	49.6
<b>PDTC</b>	49	18.8
<b>UDRA</b>	53	20.4
<b>PDTI</b>	2	0.8
<b>PDAO</b>	23	8.8
<b>UDMA</b>	1	0.8
<b>Transferred</b>	2	0.8

**Key:** UDDO=unplanned discharge dropped out; PDTC=planned discharge therapy complete; UDRA=unplanned discharge refused appointment; PDTI=planned discharge therapy incomplete; PDAO=planned discharge assessment only; UDMA=unplanned discharge moved away.

\*Discharge data unavailable for 8 cases

Table 2. Number of referrals for anger problems per annum, including whether discharge was planned or unplanned

Year	n	Missing	Planned	Valid %	Unplanned	Valid %
1995	1	0	0	0	1	100
1996	13	0	3	23.1	10	76.9
1997	25	1	7	28	18	72
1998	18	1	13	72.2	5	27.8
1999	24	2	10	41.7	14	28.3
2000	22	0	4	18.2	18	81.8
2001	40	1	20	50	20	50
2002	73	2	13	17.8	60	82.2
2003	44	1	6	13.6	38	86.4

Table 3. Number of sessions attended by the planned and unplanned discharge groups

	Planned (n=76)	Unplanned (n=184)
Median	4	1
Mean	5.18	1.93
SD	5.42	2.83

No. Sessions	Frequency	%	Frequency	%	X <sup>2</sup> (df)	p
0	2	2.6	58	31.5	40.78 (2)	0.000
1-3	32	42.1	88	47.8		
4+	42	55.3	38	20.7		

Table 4. Number of DNAs by the planned and unplanned discharge groups

	Planned (n=76)	Unplanned (n=184)
Median	0	1
Mean	0.93	1.77
SD	1.42	1.46

No. DNAs	Frequency	%	Frequency	%	X <sup>2</sup> (df)	p
0	41	53.9	18	9.8	59.80 (1)	0.000
1+	35	46.1	166	90.2		



Table 5. Source of referral for the planned and unplanned discharge groups

Planned  
(n=76)

Unplanned  
(n=184)

Source	Frequency	%	Frequency	%	$\chi^2$ (df)	p
GP	56	73.7	138	75.0	3.29 (3)	0.350
Psychiatry	19	25.0	44	23.9		
Self	1	1.3	0	0		
other	0	0	2	1.1		

Table 6. Therapy outcome for the planned and unplanned discharge groups

	Planned (n=76)	Unplanned (n=184)
Median	4	3
Mean	3.76	3.41
SD	1.03	1.27

Outcome	Frequency	Valid %	Frequency	Valid %	X <sup>2</sup> (df)	p
Worse/No Change	6	16.2	25	51.0	11.08 (1)	0.001
Some/Much Improvement	31	83.8	24	49.0		
Assessment Only*	14		25			
Missing	25		110			

\*Not included in Chi square analysis

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## **Chapter 2**

### **Systematic Literature Review**

**Caregiver burden and its relationship with social support, coping or residential transitions: A systematic review of the literature on adult offspring with intellectual disabilities and on adult offspring with mental illness.**

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[Prepared in accordance with guidelines for *British Journal of Clinical Psychology*

(see Appendix 2.1)]

**TITLE:** Caregiver burden and its relationship with social support, coping or residential transitions: A systematic review of the literature on adult offspring with intellectual disabilities and on adult offspring with mental illness.

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## **ABSTRACT**

**PURPOSE** This review examined stress or caregiver burden in mothers of adult offspring with either intellectual disability (ID) or mental illness (MI), and its effects on or associations with social support, coping or residential transitions or planning for such transitions.

**METHODS** A systematic search of Medline, Embase, PsychINFO, CINAHL, ASSIA, ERIC, Social Services Abstracts and Sociological Abstracts was undertaken, along with reference searches. Studies were selected if mothers of adult offspring with MI or ID, stress/burden and transitions, social support or coping were described in the title or abstract and original data were included.

**RESULTS** The search produced 108 articles. Of these, 18 met the inclusion criteria for containing satisfactory data. Eight studies investigated burden and social support (2 in mothers of adult offspring with ID, 5 in mothers of adults with MI and 1 considered both), 3 studies investigated burden and coping (1 in mothers of adults with ID and two making a comparison of the two) and 7 studies burden and residential transitions (5 in mothers of adults with ID, 1 in mothers of adults with MI and 1 compared the two).

**CONCLUSIONS** High quality studies examining the above factors in mothers of adult offspring with either MI or ID were scarce. In general, both groups benefited from social support, although mothers of adults with MI were more vulnerable to distress. The benefits of problem- versus emotion-focussed coping for both groups were highlighted, as were the differences between the groups in factors leading to the offspring leaving home – stress of mothers of adults with MI and declining caregiving capacity for mothers of adults with ID. Planning for transitions was associated with lower stress in both groups. Future studies should broaden the participant base and more directly address the similarities and differences in caregiving challenges for these two groups of mothers.



## INTRODUCTION

The families of individuals with intellectual disability or mental illness have become a substantive area of research interest over recent years (see for example Blacher et al 2005). Although the 'impact' of such an individual on family members or family functioning is still a major theme in such work, investigations have also been undertaken of family involvement across the lifespan and transitions, such as planning for future care and residency. Research on the stress process (Ensel & Lin 1991, Pearlin 1989) has shown that coping and social support are two resources that influence the extent to which a stressful situation, such as residential transition, affect psychological well-being.

There is now a substantial body of evidence to suggest that the parents of offspring with intellectual disabilities are likely to experience significantly higher levels of stress than are parents of non-disabled offspring (e.g. Rodrigue et al. 1990, Dyson 1993, 1997, Roach et al 1999). However, as Hassall et al. (2005) point out, these parents vary considerably in the amount of stress they experience, and that the stress is associated with a wide range of variables, ranging from the severity of the child's intellectual disability to specific characteristics associated with the disability, such as level of communication or challenging behaviour.

It could, however, be argued that parents of non-disabled individuals do not represent an appropriate basis for comparison. In order to specifically investigate the effects of parenting an individual with intellectual disabilities, it may be more fitting to use a comparison group that has more in common with parents of individuals with ID. As lifespan expectations have increased for both parents and offspring, and given the fact that the majority of adults with ID continue to live with their parents (Eyman & Borthwick-Duffy 1994), such parents continue to offer caregiving over a longer

period, fulfilling the description of them as “perpetual parents” (Jennings 1987).

Most of these dependent adults will ultimately outlive their parents.

An established comparison group for parents of adults with ID is that of parents of individuals with mental illness (MI). Previous research has shown that mothers of adults with ID report more gratifications and less subjective burden, than ageing mothers of adults with MI (Greenberg et al. 1993a).

As Kim et al (2003) point out, parents of adults with intellectual disabilities or adults with major mental illness face similar but distinct stresses. Their experiences are similar in that they may share feelings of loss and grief associated with the realisation that their offspring will not experience a ‘normal’ life. Furthermore, both ID and MI are chronic conditions which may limit the extent to which an individual can live independently in the community without support. As a consequence of this limitation, parents of individuals with MI or ID share many caregiving tasks in common, in areas such as personal hygiene, transportation, money management and medication. These support needs can lead to parental concerns about their offspring’s future when they will no longer be able to provide the needed care or supervision to their offspring (Wasow & Wikler 1983). As social support has been shown to be an important resource in maintaining psychological well-being in parents of young children with ID (e.g. Krauss 1993), it follows that this may be similar in parents of adults with ID or indeed MI.

There are also several distinct differences between caregiving experiences that mark out these two groups. The first of these is that whereas intellectual disability is generally diagnosed, if not at birth, then within the first few years of life, the onset of MI generally occurs during adolescence or young adulthood. A second major difference between these two groups of mothers is the degree of stability or

predictability over time. The course of ID is generally fairly stable both cognitively and functionally (Eyman & Widaman 1987) and parents tend to experience more predictable caregiving demands (Wikler 1986), although the amount of burden or stress they experience may be related to the level of learning disability. However, in MI there is less predictability. Longitudinal studies have found that around a third of people with MI improve over time, another third remain stable and the final third show progressive decline in functioning (Harding 1988). Within these groups, there are of course fluctuations in functioning.

Some researchers have adopted a stress process model in order to provide a theoretical framework to investigate this type of question (e.g. Greenberg et al. 1997a; Kim et al 2003). In accordance with this perspective, stressors associated with caregiving such as amount of direct care, behavioural or social difficulties and physical health problems are conceptualised as chronic strains that may produce psychological distress (Pearlin & Schooler 1978). Previous research has shown that other enduring role strains have been risk factors for increased psychological distress, a pattern which could be expected to be associated with chronic strain in parenting an adult child with a disability. The investigation of caregiving provides opportunities to examine how resources such as social support and coping strategies are related to psychological outcomes. Previous research has shown that in carers generally, perceived inadequacy of social support is related to poorer mental health (George & Gwyther 1986). Seltzer and Krauss (1989) found that mothers of adults with ID who had larger and more satisfying social relationships reported better morale and less stress. Major transitions in the offspring's life which may cause stress for parents occur at times most other parents experience a freedom from caregiving responsibilities. Planning surrounding decisions about the future residence of disabled offspring is highly emotive, more so than financial and legal

arrangements. Smith et al (1995) suggest this is because parents have to face the fact that at some point their offspring will no longer reside in their life-long home.

The majority of research studies investigating the effects of parenting a child with a learning disability have employed mothers as the participants. Hauenstein (1990) suggests two reasons for this imbalance. Firstly, mothers are generally the primary caretakers when the offspring lives at home, and secondly, they are their offspring's main representative to health care providers.

There are a number of similarities and differences that have been noted between mothers of adult offspring with intellectual disability and mothers of adults with mental illness. The question of interest for this review is, what are the associations between caregiver burden or psychological well-being and social support, coping strategies or residential transitions themselves or planning for them for these two groups of mothers?

This is an important area of research because the consequences of caregiver burden or significant decline in psychological well-being can have far-reaching consequences. These consequences can affect both mother's and offspring's quality of life, and caregiver resources available for dealing with further stressors such as residential transitions or planning for such events. Inadequate planning can be potentially damaging and disruptive. Parents have to cope with their worries about the future, whilst their offspring's quality of life may be at stake. Their freedom of choice and capacity to deal with the loss of the parent may be affected. In their investigation of specific help for parents in planning for future care, Botsford and Rule (2004) stated that unplanned transitions sometimes arise as a consequence of psychological distress and may be connected with inadequate resources such as social support or coping. Such transitions are associated with reduced capacity to

cope, depression, and psychiatric crises for the offspring. There is reduced capacity for continuity of care and appropriate placements may not be immediately available. These factors may affect service cost and delivery.

## **OBJECTIVE**

The objective of this review was to present the best available information related to maternal caregiver burden and its association with coping strategies, social support or residential transitions, drawing on ID and MI literature. This review summarises the findings of relevant studies in English published between 1995 and 2005 in peer-reviewed journals. The specific objectives of this review are to:

- Investigate maternal caregiver burden in mothers of adults with ID or MI, and specifically its association with coping, social support or residential transitions.
- Summarise the evidence relating to these factors in the two groups of ID and MI in order to allow comparisons between them.

## **METHOD**

A systematic search strategy was implemented. This involved searching the following electronic databases: MEDLINE, Embase, PsychINFO, CINAHL, ASSIA, ERIC, Social Services Abstracts, Sociological Abstracts from 1995 up until October 2005. The review used a keyword search strategy with PARENTS, AGING/AGEING/OLDER/ELDERLY, ADULT OFFSPRING, STRESS, CAREGIVER BURDEN, MENTAL ILLNESS/DISORDER, LEARNING DISABILITY/INTELLECTUAL DISABILITY/MENTAL RETARDATION as the main search terms, and COPING, SOCIAL SUPPORT and RESIDENTIAL TRANSITION as secondary search terms. Reference searching and hand-searches of selected journals were also carried out (see Appendix 2.2).

**Inclusion/Exclusion Criteria**

Studies were included if they contained original data pertaining to mothers of adults with intellectual disabilities or mothers of adults with major mental illness and investigation of caregiver burden or stress, and also investigated at least one of the three areas of interest (coping, social support or residential transitions/planning thereof). They must have been published in peer-reviewed journals in English. The complete dataset produced by the search strategy was assessed initially by title for relevance and a number discarded at this point, including dissertations and case studies. The Abstracts of the remaining references were obtained and further decisions on relevance made at this point, further reducing the dataset. Twenty four articles were obtained, and a further six discarded as on close reading it became clear they did not meet inclusion criteria. This then left only the included studies.

**Analysis**

The methodological quality of the included studies was assessed using an 11 item checklist constructed specifically for the review. The items for this checklist were derived from a number of sources, including the University of York NHS Centre for Reviews and Dissemination (2001), the Critical Skills Appraisal Programme and Walburn et al (2001). The checklist focussed upon variables most often highlighted in critical appraisal, including justification of sample size, sampling, validity of measures and generalisability of the findings (see Table 1). The second reviewer also rated methodological quality, on a randomly selected sample of the included studies (3 studies).

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INSERT TABLE 1 ABOUT HERE  
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As anticipated, statistical investigation was not appropriate, so findings were summarised in narrative form.

## RESULTS

The search strategy produced 108 articles. Of these, 18 met the inclusion criteria. Eight studies investigated mothers of adult offspring with ID, 6 investigated mothers of adult offspring with MI and 4 studies looked at both. Seven studies looked at residential transitions, 5 using a population of mothers of adults with ID, 1 using a population of mothers of adults with MI and 1 comparing the two groups. Only 3 of the included studies investigated coping and caregiver burden, 1 from the ID literature and two comparing mothers of adults with either MI or ID. Eight of the included studies investigated social support and caregiver burden. Five of these drew on mothers of adults with MI, 2 on mothers of adults with ID and 1 compared the two.

Eleven studies were cross-sectional surveys, 6 of these dealing with social support and 4 with residential transitions, one of which was cross-cultural. One also dealt with coping. Seven were longitudinal studies, 2 dealing with social support, 3 with residential transitions and two of the studies were on coping. The sample size (mothers only) of the studies ranged from 18 to 744 (median 193). The total number of mothers was 4491. In investigating caregiver burden and social support, the majority of studies applied existing measures of burden, stress, well-being and social support. The exceptions to this were; i) the Hong (2003) study which devised a measure of social support, ii) the St Onge (1997) study used specially constructed scales for perception of daily living support and health, and iii) the Greenberg (1997) study which used specially devised scales for sources of maternal stress and offspring behavioural problems. Two studies reported specially modifying scales (Greenberg 1995, measurement of support & assistance; St Onge 1997, using the Greenberg 1995 modified support & assistance scale and also a modified measure of objective burden). In one study, the measures were translated in to French (St Onge 1997) and in another, Hebrew (Rimmerman 2001).

For those studies investigating caregiver burden and coping, all of the included studies applied existing measures of burden, coping and depressive symptoms, although some subscales were omitted. Kim (2003) further used specially constructed measures of offspring behaviour problems and pile-up of stressors.

Again, in investigating caregiver burden and residential transition, the majority of studies applied existing measures of burden, depressive symptoms and stress. Similarly, every study devised a measure of residential transition or planning for transition. Two studies modified existing measures (Pruchno 1999 & Smith 1995, both measures of offspring functional ability). A number of the included studies devised specific instruments; for example Seltzer (1997) included a measure of caregiving challenges; Essex (1997) had constructed measures of stress and caregiver resources; Smith (1995) devised a measure of extent of caregiving and Seltzer (1995a) included specially constructed measures of offspring reliance on the mother and maternal physical and social well-being.

The characteristics of the included studies and scales used are described in Tables 2 to 4.

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INSERT TABLE 2 ABOUT HERE  
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INSERT TABLE 3 ABOUT HERE  
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INSERT TABLE 4 ABOUT HERE  
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The quality of the studies was mixed. Their performance on the checklist shown in Table 1 and marks scored was in the range of 4-9 out of a possible 11 (mean score = 67.1%). The studies performed best for: 'demographic details', 'appropriate analysis'



and 'conclusions justified from findings', all included by 100% of studies. All but 2 of the studies stated their inclusion and exclusion criteria (Smith 1995; Schwartz 2002). However, none of the studies included a sample size calculation or justification of sample size. Similarly, only 2 discussed whether or not the sample was in any way representative of the population they were aiming to investigate.

### **Caregiver burden and its association with social support**

Five of the 8 included studies had populations of mothers of adults with MI, 2 had mothers of individuals with ID and one compared the two groups. Of the included studies, two found specific effects of age on social support and burden, both of them investigating mothers of offspring with ID. Hong (2001) found that an increase in support (emotional support for mothers 65+ or both emotional support and network size for those under 65) lead to an increase in psychological well-being. Rimmerman (2001) found significant results only in those mothers aged 68+, that those with greater social support and perceived control had greater life satisfaction. Two studies investigated offspring with MI as sources of social support to their mothers, both finding that support and assistance provided by them was related to lower levels of subjective burden (Greenberg 1995; Schwartz 2002). However, Schwartz (2002), in the embedded sample of mothers (analysed in one group with fathers), found that if both objective and subjective burden was lower, parents reported feeling that they received more support from their offspring.

Only one study looked at the effect of support group membership on caregiver burden, and that in a sample of mothers of adults with MI embedded in a general group of parents (Cook 1999). This study found that burden was significantly reduced in members compared to non-members, despite being reportedly more vulnerable. No comparison is available for mothers of adults with ID.

The St-Onge (1997) study highlights elevated distress levels in women caring for adult offspring with MI, and their association with feelings of confinement and isolation – few participants had friends who were confidants. This chimes with the Greenberg (1997) study of mothers of adults with either ID or MI. In this comparison study, mothers in the MI group had smaller social networks, and social support was more predictive of change in burden and depressive symptoms in this group than mothers of ID individuals. For the mothers of individuals with ID, there was no direct effect of social support on well-being. Furthermore, the authors concluded that there was no evidence that support buffers the effects of stress on depressive symptoms in either group. However, Kaufman (1998), in another embedded sample of mothers (in a group of parents of both genders), found that the majority were coping with stress, and that social support moderated the effects of stress.

Few of the included studies mentioned basing their work on specific models. Hong (2001) mentions the 'social convoy' model and socioemotional selectivity theory and Rimmerman (2001) and Greenberg (1997) and (1995) describe a stress process model of chronic strains such as level of caregiving mitigated by resources like social support having a beneficial effect on manifestations of stress. Only the Greenberg (1997) study allows for the comparison of mothers of ID or MI adults within a specific model of stress and burden and social support.

Only one of the included studies (Hong 2001) fails to mention characteristics of the offspring, such as diagnosis, chronicity, severity or level of ID. However, such characteristics are not reported as having a bearing on the findings. The quality ratings of these studies were generally high. The findings of those studies losing more marks were often supported by studies with a greater quality rating, suggesting that despite any drawbacks, their conclusions were generally sound.

## **Caregiver burden and its association with coping**

Only three studies meeting inclusion criteria investigated the association between caregiver burden and coping. Kim (2003) compared changes in coping over time between mothers of adults with ID and mothers of adults with MI and found that in both groups, an increase in emotion-focused coping predicted a decrease in psychological well-being. Furthermore, for the mothers in the ID group, an increase in problem-focused coping led to reduced distress and an improvement in the quality of the mother-child relationship. However, for the mothers in the MI group, an increase in problem-focused coping had no effect on distress but did have a similar effect on the relationship. Notably, mothers in the MI group were more likely to use emotion-focused coping styles. Seltzer (1995b) compared coping styles in mothers of adults with either MI or ID, but in a cross-sectional survey. No differences were found in the degree of problem-focused coping exhibited by the mothers, but mothers of adults with MI used more emotion-focused coping which predicted an increase in maternal depressive symptoms. Mothers of adults with MI tended to fare worse, with higher stress and depressive symptoms. This study showed that the same coping strategies could produce different outcomes, highlighting the differences between these groups of mothers. Predictability and expectations may have contributed to these findings. The Essex (1999) study investigated mothers' and fathers' coping styles in parents of adults with ID over time, and found no difference between the parents in the amount of emotion-focused coping, but also found that mothers were significantly more likely to use problem-focused coping strategies than fathers. For mothers specifically, an increase in problem-focused coping and decrease in emotion-focused coping buffered the impact of stress on psychological well-being.

Both Kim (2003) and Seltzer (1995b) specifically mention working within a theoretical model, namely a stress and coping paradigm, with stresses from caregiving and pile-up of other life events leading to psychological distress. However, all the studies

describe offspring characteristics such as diagnosis and level of ID, although similarly to the studies investigating social support, they are not always reported as having a bearing on the findings. Notably, all three of these studies utilise participants drawn from the same sample from a large, ongoing longitudinal study. However, the quality ratings for these studies were consistently at the higher end, suggesting that credence can be placed in their conclusions.

### **Caregiver burden and its association with residential transitions**

Five of the included studies assessing residential transitions or planning for change in residence did so with samples of mothers of adults with ID. One study had an embedded sample of mothers within a population of parents of adults with MI (Rimmerman 1995), and one study compared mothers of adults with either ID or MI. Notably, four of the studies drew at least some of their participants from the same source, that of the large, ongoing longitudinal study mentioned above (Seltzer 1997; Essex 1997; Freedman 1997; Seltzer 1995a).

In a direct comparison of mothers of adults with ID or MI, Seltzer (1997) found that the consequences of the end of co-residence were similar between the two groups (reduced levels of subjective burden but no change in depressive symptoms), but antecedents to transition differed markedly. In the ID group, transition was associated with reduced caregiver capacity, but in the MI group transition appeared to be related to stress. Another longitudinal study, that of Essex (1997), utilised participants from the same source as the Seltzer (1997) paper. Unsurprisingly, the Essex (1997) study found that an increase in awareness of age-related changes (perhaps akin to caregiving capacity) predicted increased perception of burden and transition to a waiting list for placement in mothers of adults with ID. However, the majority avoided planning for future care. This finding is repeated in the Freedman (1997) study, that fewer than 50% of participants had made plans for future

residency. However, again, the population was derived from the same source. This study further found that, of those mothers of adults with ID who did make plans, 'short term planners' (wanting a placement within 2 years) had significantly lower well-being than 'long term planners' (not wanting a placement within 2 years).

Other studies found a relationship between stress or burden and the types or stage of plans. Pruchno (1999) found that in a cross-sectional study of mothers of adults with ID, caregiver burden mediated the stressor-outcome relationship and increased burden led to more plans for formal placement and fewer plans for the adult to be placed within the family. Smith (1995) found that the stage of planning for residential transition was directly affected by factors such as use of services, perception of reduced caregiver capacity and indirectly by perceived need for services and objective and subjective burden. In the Seltzer (1995a) paper, planning for residential transition was seen as a coping mechanism. In this cross-cultural study, the sample who were the poorest planners (the Northern Irish sample) had the poorest well-being and highest stress levels, compared to the sample most likely to plan (the US sample) who had the highest levels of well-being and lowest stress levels. In a similar vein, in the only study whose sample of mothers of adults with MI was embedded in a group of parents of both sexes (Rimmerman 1995) found that the likelihood of planning for residential transition was associated with lower stress levels.

Few of the included studies based their work on specific theoretical models. Of those that did, Essex (1997) mentions a general stress process model, and both Pruchno (1999) and Smith (1995) used an ABCX model of stressors, resources and appraisals affecting outcome through direct and indirect effects.

All of these included studies described characteristics of the adult offspring such as diagnosis, chronicity, level of ID and so on, and many included these as potential

sources of stress in their analyses. The quality ratings of these studies covered the full spectrum, including both the highest and lowest rated studies. This would suggest that any conclusions drawn about the effect of planning for transitions on stress in mothers of adults with MI should be tentative.

## **DISCUSSION**

There were few data in the literature concerned with the association between caregiver burden or parental stress and social support, coping or residential transitions in either mothers of adult offspring with intellectual disabilities or mothers of adults with mental illness. The split between those investigating mothers of ID individuals and those using samples of mothers of adults with MI was fairly even across the board. Studies considering the association between burden and social support were weighted more towards mental illness, and those considering coping or residential transitions included more samples of mothers of adult offspring with intellectual disabilities. Notably, only three studies met inclusion criteria which investigated coping and burden, despite the fact that this could be considered a major topic of interest relating to mothers of adults with disabilities, either intellectual or psychiatric. However, it should be noted that each of the issues of interest to this review related to caregiver burden contained a study that directly compared these two groups of mothers. It could be argued that this highlights the importance of these issues for these populations.

Many of the studies were of the cross-sectional survey design (11 out of 18), and although this is appropriate for identifying associations, the nature of the data obtained makes inferences regarding causality very difficult. More complex longitudinal designs could appropriately be used to assess the effects of, for example, different stressors or changes in social networks over time. Seven of the included studies did utilise longitudinal designs, and these were fairly evenly split

between those studies investigating social support or residential transitions and burden, and two out of the three studies on coping styles.

### **Data quality**

The scarcity and somewhat mixed quality of the studies may make generalisations from the findings more problematic. The studies investigating the three areas of interest did not consider the same issues in the two groups of mothers, so amalgamating the findings may not be appropriate. The different measures used, the different underlying aims or research questions and different models could also make comparison between the studies difficult. The majority of studies used participants drawn from the same large population involved in a longitudinal study (Essex 1997; Pruchno 1999; Freedman 1997, Seltzer 1995a, b, 1997, Essex 1999, Kim 2003, Greenberg 1995, 1997 and Hong 2001). This again would suggest that the generalisability of the overall findings is limited, as comparing different findings from the same population is problematic and could be considered to confound any conclusions that one might draw. The fact that the samples were largely self-selected may also have affected the general utility of the findings. Several of the studies show that, although there may be differences between mothers of adults with ID or MI in their coping styles, social supports or perception of burden, generally levels of stress or burden were quite low. This may be due to the fact that mothers experiencing a high level of stress are less likely to volunteer for this type of research.

None of the studies formally sought a sample that was representative of all mothers of adult offspring with either ID or MI facing the prospect of continuing caregiving demands on them. However, the majority of the included studies acknowledged the problems inherent in their samples.

## **Association between caregiver burden and social support in mothers of adults with either ID or MI**

It is clear from the included studies that dependable social support from a variety of sources has a generally positive effect on psychological well-being for both groups of mothers. Both Hong (2001) and Rimmerman (2001) noted age-related effect of social support in mothers of adults with ID, highlighting its dynamic nature across the life course. Hong (2001) found that, for the younger group of mothers, an increase in network size and thus support produced enhanced well-being only in mothers who were not legal guardians of their offspring. This underscores the importance of long term planning for the related issue of transitions, as guardianship could be transmitted to a successor caregiver. These studies stress the importance of social support in maintaining and enhancing well-being in later life. Interestingly, support given by the disabled offspring was only considered in mothers of adults with MI. Given the fact that both studies doing so emphasised caregiving as an enriching experience and acknowledge the practical contributions made by such offspring, it is surprising that this has not been considered in adults with ID, as such parents have been reported to generally experience greater caregiving rewards. However, Rimmerman (2001) did conclude that single mothers caring for their adult offspring with ID at home derive support and companionship from them, although this was not investigated directly. In the only paper to directly compare these two groups of mothers on levels of stress and social support and how these predict caregiver burden and depressive symptoms (Greenberg 1997), the findings were broadly in line with what the previous literature would suggest. Mothers of MI individuals were more vulnerable and more isolated, a finding supported by Schwartz (2002). They were also more likely to belong to a support group and to derive benefit from this. It seems that social support is a more important resource for mothers of adults with MI than ID, and this may be related to predictability. Life course is less predictable for



parents of individuals with MI, as the course of illness is fluctuating, and medications and services change, underlining the need for reliable support.

In summary, both mothers of adults with MI and mothers of adults with ID derive considerable benefit from social support. However it seems that mothers of adults with MI started from a position of greater vulnerability, perceiving their caregiving role as more burdensome. Only two of the studies utilised a longitudinal design, the rest relying on cross-sectional surveys, so firm conclusions about causality cannot be drawn.

#### **Association between caregiver burden and coping in mothers of adults with either ID or MI**

Conclusions drawn from the three included studies considering this area of interest should be tentative, due to the fact that all drew on the same population for their sample of mothers of adults with ID, and two for their sample of mothers of adults with MI. Indeed, conclusions should be drawn with caution generally if only based on three papers. However, it could be argued that the main point in practical terms would be to acknowledge the possible counter-productive effects of emotion-focused coping on psychological well-being and to encourage more problem-focused coping in these groups of mothers. In the Kim (2003) study and the Seltzer (1995b) study, both comparing the two groups of mothers, it was found that mothers of adults with MI were more likely to use emotion-focused coping strategies. This may be related to Folkman's (1984) suggestion that such strategies are more likely to be employed in situations where there is little opportunity to exercise control, such as caring for someone with mental illness. Again, this may relate to the issue of predictability. The fact that two of the studies were longitudinal in design and showed changes in coping strategies over time highlights the dynamic effects of coping on burden even

in later years of caregiving when it could be argued that both groups of mothers have become familiar with the challenges facing them.

In summary, the studies highlighted the role of problem-focused coping in promoting psychological well-being and the potentially detrimental role of emotion-focused coping in both groups of mothers. However, as highlighted in the previous section on social support, mothers of adults with MI could be seen to be in a worse position than mothers of adults with ID and they are more prone to use emotion-focused coping as they have less perceived control over the situation. It must, nevertheless, be reiterated that conclusions must be tentative due to the small number of studies and the fact that the same population has been used in both.

#### **Association between caregiver burden and residential transition in mothers of adults with either ID or MI**

The included studies considering this area of interest were weighted more towards samples of mothers of adults with intellectual disabilities. However, as noted above, many of them drew on the same population, making drawing conclusions difficult. Although few of the studies investigated actual transitions, many considered planning for transition. This highlighted the emotive content of this issue, as mothers have to face declining caregiver capacity and their own mortality and plan for their offspring leaving the family home.

Many of the studies found some association between transition or planning for transition and caregiver burden or stress, whether in stage of planning or the types of plans being made. It may be that increased stress or looming worries about the future placement of their offspring would appear have a detrimental effect on the resources available to deal with transitions or planning. However in some cases it may precipitate transition to a waiting list for placement or the offspring actually

leaving the family home. It is difficult to draw any firm conclusions about differences between these two groups of mothers due to the preponderance of studies only considering the ID population. However, in the paper directly comparing the two, there were clear differences in the causes of the offspring leaving home. For the mothers of ID individuals, the reason given for leaving was declining caregiver capacity and for mothers of adults with MI, stress was more of a predictor. Consequences of the end of co-residence were similar for the mothers. This serves to highlight both the similarities and differences between these two groups of mothers, and relates to suggestions from previous literature about the general and specific effects of caregiving (e.g. Pruchno et al. 1995, Greenberg et al 1993). These are indicative of the complex nature of caregiving and the demands of different types of disabilities, which may be connected with variation in predictability. These findings serve once again to highlight the importance of proper planning for transitions and its relationship to social support and coping.

In summary, it would appear that the factors leading to the offspring leaving home differed between the two groups of mothers. For mothers of adults with ID, awareness of age-related changes or declining caregiving capacity was more key, but for mothers of adults with MI, stress was more of a factor. This again may be related to predictability of care needs and life course. However, for both groups, actual planning for transitions could be viewed as a positive, as it was associated with lower stress and may be a coping mechanism. Planned transitions may be associated with respect for offsprings' wishes, which again may mediate stress. Although the studies were fairly evenly weighted between longitudinal and cross-sectional designs, making comparisons between the two groups of mothers is problematic due to the high proportion of ID studies.

## **Limitations and future directions**

The findings of this review tend on the whole to highlight the fact that these two groups share many similarities. However, differences are also noted, principally qualitative in nature. Many of the included studies used the same cohort of mothers of adult offspring with intellectual disabilities or mental illness, making it difficult for subsequent researchers to draw firm conclusions. Notably, a sample of UK-based mothers from Northern Ireland was included in only one study, an investigation of caregiver burden cross-culturally. As this group fared worst in measurement of psychological well-being, it would be of interest to investigate whether this finding could be generalised to a wider UK sample.

Despite coming under the same broad topic heading, many of the studies of mothers of offspring with ID or MI did not address the same question directly. Given that these two groups share many similarities as well as having a number of qualitative differences, there would be some purpose in investigating these more directly.

Interestingly, although the majority of studies recorded characteristics of the offspring with disabilities, such as diagnosis, chronicity, level of intellectual disability and so forth, fewer directly considered these as possible sources of maternal stress or contributors to burden. Indeed, given that differences in predictability have been emphasised as caregiver challenges for these groups of mothers, it is surprising that more studies have not investigated this.

**Table 1. Checklist results: quality of all included studies**

Study (first author & year)	Explicit question?	Discussion of sample representativeness	Inclusion/Exclusion criteria stated	Demographic details	Justification of sample size	Justification of validity/reliability of measures	Response/drop-out rate specified	Response/drop-out rate justified	Appropriate analysis	Discussion of generalisability	Conclusions justified from findings?	Marks lost	% of max quality score
Hong 2001	+	-	+	+	-	+	+	+	+	+	+	2	81.8
Essex 1999	+	-	+	+	-	+	+	+	+	+	+	2	81.8
Seltzer 1997	+	-	+	+	-	+	+	+	+	+	+	2	81.8
Kim 2003	+	-	+	+	-	+	+	+	+	+	+	2	81.8
St-Onge 1997	+	-	+	+	-	+	+	-	+	+	+	3	72.7
Essex 1997	+	-	+	+	-	-	+	+	+	+	+	3	72.7
Kaufman 1998	-	-	+	+	-	+	+	+	+	+	+	3	72.7
Greenberg 1997b	+	-	+	+	-	+	+	+	+	-	+	3	72.7
Seltzer 1995b	+	-	+	+	-	+	-	-	+	+	+	4	63.6
Freedman 1997	+	-	+	+	-	-	+	+	+	-	+	4	63.6

Pruchno 1999	+	-	+	+	-	-	-	+	-	+	+	-	+	+	+	4	63.6
Smith 1995	+	+	-	+	-	-	-	+	-	+	+	+	+	+	+	4	63.6
Schwartz 2002	+	-	-	+	-	-	-	+	+	+	+	+	+	+	+	4	63.6
Greenberg 1995	+	-	+	+	-	-	-	+	+	-	+	+	+	+	+	4	63.6
Cook 1999	+	+	+	+	-	-	-	+	-	+	+	+	+	+	+	4	63.6
Seltzer 1995a	+	-	+	+	-	-	-	-	+	-	+	+	+	+	+	5	54.5
Rimmerman 2001	+	-	-	+	-	-	-	+	+	+	+	+	+	+	+	5	54.5
Rimmerman 1995	+	-	-	+	-	-	-	-	-	-	+	+	+	+	+	7	36.4

+ = Present; - = Absent

**Table 2. Characteristics of included studies investigating caregiver burden and social support in both ID and MI (study denoted by first author and year of publication)**

Study	Design	Participants	n	Measures	Summary of Findings
Hong 2001	Longitudinal survey repeated measures	Sample derived from a larger longitudinal study; mothers aged 55+ with offspring with ID living at home; recruited through agencies, media or other participants.	251	Psychological Well-being: 2 subscales of Ryff's positive psychological functioning scale: purpose in life and personal growth. Social support: personal interview derived for the study from the convoy model of social networks, measuring network size and amount of emotional support.	Maternal age conditions effects of social support: 65+, increase in amount of emotional support from networks predicted increase in psychological well-being but change in the number of network members was not related to change in well-being. For women aged 65 or younger, increase in size and emotional support predicted increased well-being only for those who were not legal guardians of their offspring.
St-Onge 1997	Cross-sectional survey	Mothers of adults with psychotic illness aged between 18 and 55 who have regular contact with them; sample recruited through hospitals and self-help groups.	99	Concern for offspring well-being: Filial Anxiety Items Factor B. Perception of daily living support given to offspring: 12 item questionnaire derived for study. Burden related to offspring disability: modified Life Skills Profile. Perception of support: Perceived Social Support from Friends and from Family. Relationship with confidant: Kaplan Intimacy & Adaptation Scale Conflict with confidant: 3-item scale derived for study Subjective perception of health: 4 item Lickert scale derived for study. Psychological distress: Psychiatric Symptom Index. (NB standardised scales translated into French)	Reported distress in this sample twice as high as the general population, but if mothers considered their offspring's condition had improved, they were less distressed than other mothers in the study. Study concentrated on burden and social support as factors associated with psychological distress and multiple hierarchical regression showed a strong association. The main factors associated with distress were concern for their offspring's well-being and feelings of confinement and isolation. More than 1/3 of participants stated they had no friends or didn't talk to friends about their offspring.

Kaufman 1998	Cross-sectional survey	Sample derived through staff identification of clients of a community mental health centre who lived with at least one parent aged between 40 and 80. Sample included both mothers and fathers, although 90% were mothers	18 mothers	Impact of offspring's illness – stressors: modified Social Behaviour Assessment Schedule. Support behaviour from social network: Social Support Behaviours Scale. Involvement in social network: Social Support Appraisals Scale.	Very small sample in an exploratory study, therefore only analysed descriptively. Majority of parents appeared to manage well with the stress and burden associated with caregiving. Most reported high levels of social support from relatives and friends. Scores on 2 social support measures were inversely related to 3 measures of caregiver distress and thus may moderate the effects of stress.
Greenberg 1997	Parallel longitudinal survey	Sample derived from a larger longitudinal study; mothers aged 55+ with offspring with ID or MI living at home; recruited through agencies, media or other participants	288 mothers of adults with ID 73 mothers of adults with MI	Sources of maternal stress: amount of care, count of daily living tasks devised for study. Number of offspring's behavioural problems, count derived from the literature for the study. Pessimism about the future, based on items from the QRS-F. Social support: network size, Antonucci's measure of social support, number of friends/relatives who are carers from same source. Support group membership, single question. Burden: Zarit Burden Inventory. Depressive symptoms: Centre of Epidemiological Studies-Depression Scale	Study concentrated on levels of stress and social support and how they predict caregiver burden and depressive symptoms. Mothers of adults with MI had smaller networks and were more likely to belong to support groups and have at least 1 friend who is also a carer. Social support was a bigger predictor of changes in burden or depressive symptoms in mothers of adults with MI. This suggests the importance of the social context for psychological well-being. The mothers of MI adults were more vulnerable than mother of adults with ID, facing more challenges such as behaviour problems or worries about the future. Only in the amount of direct care did mothers of ID adults fare worse. Little evidence for direct effect of social support on well-being from this group. Pessimism about the future predicted increased depressive symptoms for the ID group but not the MI group. Larger network reduced depressive symptoms for women in the ID group but no the MI group. No evidence that sources of support buffer the effect of stress on depressive symptoms.



Greenberg 1995	Cross-sectional survey	Sample derived from a larger longitudinal study; mothers aged 55+ with offspring with MI living at home; recruited through agencies, media or other participants	105	Subjective burden: Zarit Burden Inventory. Sources of stress: objective burden, modified Objective Burden Scale, offspring's psychiatric symptoms, General Psychopathology Scale. Amount of support provided by offspring: modified instrument from the National Survey of Families and Households, Measurement of Support & Assistance of Adult Children to Parents.	Study looked specifically at offspring with MI as sources of support to their parents within a general stress framework including sources of stress, resources and manifestations of stress. Majority of mothers reported at least some ongoing help with daily living tasks, and that such help/support was significantly related to lower levels of maternal subjective burden. Offspring with MI therefore valuable sources of social support, not just a burden on the family.
Schwartz 2002	Cross-sectional survey	Israeli study, sample recruited from self-help support groups, consisting of parents caring for adult offspring with MI living with them. 86% of participants were mothers.	80 mothers	Amount of support provided by offspring: Measurement of Support & Assistance of Adult Children to Parents modified by Greenberg (above). Gratifications of caregiving: 8 item Lickert scale from Greenberg 1994. Subjective burden: Zarit Burden Inventory. Objective burden: modified Tessler Care Scale.	Study investigated levels of assistance and support and the perception of their own caregiving as mentally & emotionally rewarding. All parents reported receiving help and support but perceived satisfaction from parental duties and learning about themselves as more important. Assessment of this satisfaction was unaffected by the subjective and objective burden on them and severity of the offspring's illness. If both objective and subjective burden were lower, parents reported feeling they received more support from their offspring, more emotional than instrumental.
Cook 1999	Group comparison cross-sectional survey	Sample drawn from larger study of relatives attending family support groups for MI or relatives of clients of community agencies who were not group members. Both parents in the sample, of whom 77% were mothers.	92 mothers	Depression: Index of Depression. Social support: Social Provisions Scale (4 of 5 subscales). Service utilisation: Family Support Services Index. Objective & subjective burden: Thresholds Family Burden Scale brief version.	Comparison of levels of caregiver burden between support group participants and non-participants, with an embedded sample of mothers. Regression analysis revealed caregiver burden was significantly lower in group participants, those with lower depression and those whose offspring had fewer unmet needs or hospitalisations. Group members reported more stresses and strains than non-members, higher levels of depression and less dependable social support but reported burden was lower in this group.

Rimmerman 2001	Cross- sectional survey	Sample drawn from individuals identified by the Israeli government as being mothers, aged 60+, of adults with moderate ID working in sheltered workshops.	160	Daily life events: Inventory of Small Life Events. Life satisfaction: Life Satisfaction Index (LSI- A). Well-being: Affect Balance Scale. Control over desired events/outcomes: Desired Control Scale. Social support: Lubben Social Network Scale. All standardised measures were translated into Hebrew.	Significant differences apparent in the group aged 68+: those with offspring at home had fewer undesired life events than those with offspring out-of- home. Mothers in 1 parent families with offspring at home had greater life satisfaction than mothers in 2 parent families with offspring at home, whereas 2 parent mothers with offspring out-of-home had greater life satisfaction and wellbeing than single mothers. Aging mothers receiving support from their social network had fewer undesired life events, and those with more social support and an increased perception of desired control had greater life satisfaction than those with less social support and desired control.
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**Table 3. Characteristics of included studies investigating caregiver burden and coping in both ID and MI (study denoted by first author and year of publication)**

Study	Design	Participants	n	Measures	Summary of Findings
Kim 2003	Parallel longitudinal survey	Sample derived from a larger longitudinal study; mothers aged 55+ with offspring with ID or MI living at home; recruited through agencies, media or other participants	246 mothers of adults with ID 74 mothers of adults with MI	Subjective burden: Zarit Burden Inventory. Depressive symptoms: Centre for Epidemiological Studies-Depression scale. Quality of parent-child relationship: Positive Affect Index. Sources of maternal stress: behaviour problems, count of 8 items derived for study; pile-up of life stressors, count of 8 life events devised for study. Emotion & problem-focused coping: Coping Orientations to Problems Experienced scale (COPE)	Study tracked changes in coping over a 3 year period and found individual variability in change over time in the use of problem and emotion-focused coping. Mothers of adults with MI were more likely to use emotion-focused coping. In both groups, an increase in the use of emotion-focused coping lead to a decrease in well-being. For mothers of adults with ID, an increase in problem-focused coping produced decreased distress and an increase in quality of the relationship. However, for mothers of adults with MI, a similar increase in problem-focused coping had no effect on distress but did improve the quality of the relationship. Showed that the association between coping and well-being is dynamic, even in chronic situations.
Greenberg 1995b	Cross-sectional survey	Sample derived from a larger longitudinal study; mothers aged 55+ with offspring with ID or MI living at home; recruited through agencies, media or other participants	389 mothers of adults with ID 105 mothers of adults with MI	Depressive symptoms: Centre for Epidemiological Studies-Depression scale. Sources of maternal stress: behaviour problems, count of 8 items derived for study; caregiving demands, count of 11 items devised for study. Emotion & problem-focused coping: Multidimensional Coping Inventory (5 subscales omitted). Maternal characteristics	Study investigated coping as a moderator of stress. No differences found between the groups in amount of problem-focused coping. MI mothers used more emotion-focused coping which predicted greater maternal depression. For mothers of ID adults, depression was a function of the offspring's behaviour problems, buffered by coping. For mothers of adults with MI, depression was a function of caregiving demands, not buffered by coping. Differences possibly due to caregiver context, predictability and control.

Essex 1999	Longitudinal survey	Sample derived from a larger longitudinal study; mothers aged 55+ with offspring with ID living at home; recruited through agencies, media or other participants. Both parents made up sample to compare coping between them.	133 mothers	<p>Depressive symptoms: Centre for Epidemiological Studies-Depression scale.</p> <p>Subjective burden: Zarit Burden Inventory.</p> <p>Pessimism about the future: Pessimism subscale from the Questionnaire on Resources and Stress (QRS-F).</p> <p>Caregiving stressors: functional limitations, modified Barthel Index; behaviour problems, scale from the Inventory for Client and Agency Planning, count of 8 items.</p> <p>Coping: emotional &amp; problem-focused coping derived from 8 subscales of the Multidimensional Coping Inventory.</p>	<p>Study examined stress and coping processes. Findings showed that mothers used the same amount of emotion-focused coping as fathers, but were significantly more likely to use problem-focused coping than their husbands. For mothers, and increase in the use of problem-focused coping and decrease in use of emotion-focused coping buffered the impact of stress on psychological well-being. For mothers of offspring with milder functional and behavioural problems, coping was less influential regulating well-being. Findings consistent with general theories of stress buffering in conditions of high stress.</p>
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**Table 4. Characteristics of included studies investigating caregiver burden and residential transition in both ID and MI (study denoted by first author and year of publication)**

Study	Design	Participants	n	Measures	Summary of Findings
Seitzer 1997	Longitudinal survey	Sample derived from a larger longitudinal study; mothers aged 55+ with offspring with ID or MI living at home; recruited through agencies, media or other participants	308 mothers of adults with ID 73 mothers of adults with MI	Residential status of offspring: coded as home or away at time2. Subjective burden: Zarit Burden Inventory. Depressive symptoms: Centre for Epidemiological Studies-Depression scale. Maternal caregiving capacity: age, marital status, health status, size of social support network. Caregiving challenges: offspring behaviour problems, count of 8 items; number of direct caregiving tasks, count of 11 items; maternal propensity to focus on & vent emotions, 4-item self-report scale derived from Carver et al (1989). Descriptives: frequency of contact when left home; continued caregiving responsibility; type of living arrangement.	Prospective 3 year study determining the antecedents and consequences of the end of co-residence. Predictors for the ID group were declining capacity, such as older maternal age and poorer health, along with being on a waiting list. No indication that the end of co-residence related to stress in this group. For the MI group, caregiver capacity was not a predictor, but stress was. Consequences for the 2 groups were similar, with a decrease in subjective burden and no change in depressive symptoms, even for mothers of adults with MI who experienced elevated symptoms. Frequency of contact high after transition in both groups. Highlights the different needs of the 2 groups.
Essex 1997	Longitudinal survey repeated measures	Sample derived from larger longitudinal study; mothers aged 55+ with offspring with ID living at home; recruited through agencies, media or other participants.	461	Stressors: measured 3 sources of stress on 3 point scales-level of ID profound to mild; physical health of offspring poor to excellent; unmet service needs up to 13 formal services needed but not received. Caregiver resources: maternal health, number of children, size of social network, number of services provided to offspring. Waiting list status: structured personal interview, waiting list status coded on or off; residential status coded at home or not	Study investigated predictors of residential planning and placement. A stress process model found some support as transition to waiting list was predicted in one group by increased awareness of age-related changes in offspring or failing maternal health increasing the perception of burden. The majority of families avoided planning.

Freedman 1997	Longitudinal survey repeated measures	Sample derived from larger longitudinal study; mothers aged 55+ with offspring with ID living at home.	340	<p>Characteristics of the adult: age, level of ID, number of behavioural problems, decline in health/functionality.</p> <p>Characteristics of the mother &amp; family: age, marital status, decline in health &amp; Family Environment Scale. Maternal psychological well-being: subjective burden, Zarit Burden Inventory; depression scale; for Epidemiological Studies-Depression scale; stress: 7 items from the Questionnaire on Resources and Stress (worry about the future); purpose in life, Scales of Psychological Well-Being</p> <p>Residential transition: structured personal interview, covering whether there were specific plans (coded yes/no), where the offspring will live in 2 years (coded same/different), what kind of setting they want (coded same/different).</p>	<p>Study focused on future residential plans and placement preferences over 3 year period. 4 subgroups identified &amp; significant differences found between them. 'Short term planners' (have plans and want a placement within 2 years) had the poorest well-being and most worries about the future. 'Long term planners' (have plans but aren't seeking placement within 2 years) have the best well-being and fewest worries about the future.</p>
Pruchno 1999	Cross-sectional survey	Sample derived from larger longitudinal study; mothers aged 60+ living with an adult child (21-59) with ID not expected to remain in family home indefinitely.	141	<p>Functional ability of offspring: Multilevel Assessment Instrument.</p> <p>Frequency of maladaptive behaviour: modified ABS: RC 2.</p> <p>Service use: count of 16 items derived for study.</p> <p>Burden: 9-item scale (Lawton et al. 1989) investigating mothers' experienced ill health effects, decreased social life, tiredness etc.</p> <p>Residential transition: personal interview covering 5 questions relating to family plans &amp; 5 relating to formal plans for future residence (coded yes/no). Concern for future well-being: 7-item scale derived for study 'worry about the future'.</p>	<p>Study investigated the effects of residential plans on mothers of adults with ID and found increased caregiver burden was associated with more extensive planning for formal services and less planning for familial placement. Increased service use was associated with greater formal planning. Planning for placement within the family and greater functional ability in the offspring was associated with fewer worries about the future. Formal plans had no association with worry about the future. Caregiver burden mediated the stressor-outcome relationship, burden leading to more formal and fewer familial plans. Highlights a dynamic process.</p>

Smith 1995	Cross-sectional survey	Community sample of mothers aged 58-96 with adult offspring with ID aged 21.	235 (226 complete)	<p>Planning for residential transition: content analysis of interview &amp; 5 stage coding scheme devised for study, ranging from 'no discussion' to 'definite residential plans'.</p> <p>Avoidance coping: Coping with Conflict Scale.</p> <p>Help from non-ID offspring: 2 items on meeting physical &amp; emotional needs.</p> <p>Perceived service need: rating of 13 support services.</p> <p>Subjective burden: Zarit Burden Interview.</p> <p>Perceived adverse age-change: 6 items assessing own aging.</p> <p>Extent of caregiving tasks: 4-item scale devised for study.</p> <p>Maternal functional disability: Shanas Activities of Daily Living Scale.</p> <p>Offspring's functional disability: adapted Index of Social Competence Scale.</p>	<p>Study tested a theoretical model of permanency planning using a double ABCX model. Found direct influence of use of services, non-use of avoidance, self-perception of age-related changes and help from non-ID offspring and indirect influence of perceived need for services, subjective burden, extent of caregiving tasks, offspring and maternal disability on stage of planning for future residency.</p>
Seltzer 1995a	Cross-cultural, cross-sectional survey	Mothers aged 55+ with an offspring with ID living at home in NI, Eire or US, recruited through agencies, parent groups or the media.	744	<p>Functional reliance on mother: revised Barthel Index, count of 31 items of daily living tasks.</p> <p>Social reliance on mother: solo social activities; leaving home without mother; overlapping social networks; day activities; respite.</p> <p>Planning for transition: personal interview covering 4 items including whether there was a successor caregiver, whether the offspring was on a waiting list, etc. (coded yes/no)</p> <p>Maternal physical well-being: self reported assessment, change, interference with activities.</p> <p>Maternal social well-being: derived from Antonucci's convoy model; size, composition, satisfaction.</p> <p>Maternal psychological well-being: Questionnaire on Resources and Stress (QRS-F), Philadelphia Geriatric Center Morale Scale.</p>	<p>Cross-national between Eire, NI &amp; US, therefore less focus on specific variables. Enormous variability across the 3 samples, but NI mothers were least likely to plan, had the poorest well-being and the highest stress. The US sample were the most likely to plan and had the best well-being. Planning was seen as a coping mechanism.</p>

Rimmerman 1995	Cross- sectional survey	Parents (69 mothers, 20 fathers) of adults with chronic MI recruited through an Israeli national association. Offspring aged 18. Mothers embedded , analysed as one group.	69 mothers	Emotional Stress: Questionnaire of Emotional Stress. Cognitive Appraisal Questionnaire. Self-Esteem: Rosenberg Self-Esteem Scale. Perceived social support: Interpersonal Support Evaluation List. Planning for transition: Out-of-Home Placement Questionnaire, 6 items coded yes/no covering consideration of placement & application. Devised for study	In looking at parents' attitudes to out of home placement, authors found that more planning was associated with lower marital and parental stress. Parents with greater internal resources and lower stress levels and a more favourable attitude towards placement. Parents with lower marital and parental stress are able to think about future placement and show intention to place when there is less domestic stress. However, stress, is not directly related to any placement behaviour.
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## **Chapter 3**

### **Major Research Project Proposal**

**An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.**

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[Prepared in accordance with *Course Guidelines for Major Research Project*

*Proposals* (See Appendix 3.1)]



## **Full Title of Project**

An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.

## **Summary of Project**

Parents' causal explanations for self-injurious behaviour exhibited by their offspring with intellectual disability is an under-researched area. Attribution research posits that people engage in attributional search after adverse or unexpected events, such as their offsprings' distressing behaviour, and these attributions may impact on parents' sense of competence in managing incidents of self-injurious behaviour and the stress they experience as a consequence. This may have a subsidiary effect of further affecting the offsprings' quality of life through affecting parents' perceptions of and behaviour towards them. Family relations literature suggests that the effect of self-injurious behaviour on parents' attributions and feelings of self-efficacy may be affected by whether incidents occur in a private or a public context. The aim of this study is to explore the nature and content of parents' naturally occurring attributions and how these relate to self-efficacy, stress and context through a combination of qualitative and quantitative methods. This may suggest areas of intervention with the aim of improving parental well-being and consequently improving management of their offspring.

## **Introduction**

Attribution theory outlines the need humans have to seek explanations for events (Heider, 1958) and suggests that the ways in which parents interpret their offsprings' self-injurious behaviour (SIB) may be a crucial process in determining how parents react both emotionally and practically. Wong and Weiner (1981) suggest that people engage in attributional search following negative or unexpected events, under which

heading self-injurious behaviour could be placed. Attribution theorists assume that individuals use causal explanations to understand, control and master their environment (Forsterling, 1988). Attributions may influence parents' emotional well-being and sense of efficacy and may impair their ability to interact optimally with their offspring, thus leading to poor management of the incident of self-injurious behaviour. Within the field of attributional research, there are several psychological models which may help to understand how parents interpret self-injurious behaviour. One that has been commonly used in the field of challenging behaviour including SIB is that of Weiner (1980). This model outlines three attributional dimensions that affect emotional responses and subsequent behaviour: 1) locus of causality (whether the cause resides within the person or the external world), 2) controllability (whether it is subject to personal influence) and 3) stability (whether the cause is likely to change). This is set out graphically in Figure 1. However, to explore the complexity for parents in understanding their offsprings' self-injurious behaviour, these dimensions could further be fractionated into similar categories used by Hyman and Oliver (2001), including 'direct internal' explanations for behaviour, meaning that it wouldn't occur if the person did not have intellectual disabilities, 'mediated internal', where the intellectual disability mediates the behaviour in some way, or 'interpersonal', where the behaviour is socially or environmentally determined.

Self-injurious behaviour (SIB) has been defined by Murphy and Wilson (1985, p15) as:

*'Any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm (includes) bruising, lacerations, bleeding, bone fractures and breakages, and other tissue damage'.*

Wisely et al. (2002) have stated that SIB presents as one of the most difficult management problems in people with intellectual disabilities (ID). It is by definition

harmful to the individual and impacts on wellbeing and quality of life. Furthermore it causes great distress in those people caring for them, and as Oliver and Petty (2002) state, poses significant challenges to clinicians. A review of SIB by Halliday and Mackrell (1998) reported prevalence rates of between 4 and 10% of people with ID exhibit SIB and approximately 90% of those with SIB have severe or profound ID (Oliver et al., 1987). SIB is associated with some medical conditions such as Lesch-Nyhan syndrome, Cornelia de Lange syndrome and frontal lobe epilepsy (Cataldo & Harris 1982). Many people who engage in SIB do so in more than one way and engage in other types of challenging behaviour (Emerson 1990, Borthwick-Duffy 1994). Younger adults and children are more at risk of exhibiting SIB, and prevalence rates are generally higher for males than females and for people who are non-verbal or communication problems, sensory impairments, particularly environmentally disadvantaged or have a dual diagnosis (Murphy & Wilson 1985, Borthwick-Duffy 1994). SIB is qualitatively different from other forms of challenging behaviour, especially for parents faced with their offspring harming themselves and struggling to understand and manage it. Although there is beginning to be support for an attributional framework for parents' interpretation of and reaction to non-disabled offsprings' behaviour (e.g. Bugental, Blue & Cruzcosa, 1989; Smith & O'Leary 1995) it is unclear whether this is applicable to offspring with ID, as parents may perceive behaviour as outwith their offspring's control and thus one would expect little attributional variability. However, research on families of people with schizophrenia has shown that an attributional model may be useful even where behaviour may be expected to be attributed to a specific cause (Barrowclough, Johnston & Tarrier, 1994). Chavira et al. (2000) have investigated mothers' attributions and emotions regarding the problem behaviours of children with developmental disabilities and provided support for an attributional framework. Parental causal explanations for challenging behaviour have been examined specifically in one genetic syndrome particularly associated with SIB (Hyman & Oliver

2001). This showed that parents made a variety of causal explanations regarding the influence of the syndrome on behaviour. This appears to be the only study examining parents' causal explanations for SIB. Allen (1999) has highlighted the need for more research on parents, as much of the work in this area has been conducted on staff groups (e.g. Hastings & Remington 1994, 1995; Bromley & Emerson 1995; Hastings et al. 1995, 1997; Dagnan et al. 1998;; Stanley & Standen 2000; Mossman et al. 2002; Jones & Hastings 2003).

Joiner and Wagner (1996) have argued that attributions can lead parents to make negative self-evaluations regarding their parenting skills. These negative self-evaluations may make a parent feel helpless, overwhelmed and incompetent. If parents make attributions internal to the self (self-blame), this is likely to reduce feelings of self-efficacy and increase stress. Self-efficacy has been identified as a key factor in terms of its relationship to a number of outcomes, including parenting stress (see Coleman & Karraker, 1998, for a review). Bandura (1989) suggests that individuals anticipate failure when they are inundated by aversive physiological arousal. Feelings of self-efficacy depend on how the situation is appraised and parents may find public displays of SIB more distressing. Low maternal self-efficacy is correlated with high levels of maternal stress (Wells-Parker et al. 1990).

However, attributions may not be fixed and self-efficacy is likely to vary for different behaviours in different contexts (Bandura, 1989). Drawing on the field of wider developmental and family relations literature introduces the notion of the immediate context of behaviour affecting carers' cognitions and thus perhaps their behavioural responses. Belief in one's capacity to parent is likely to affect the level of stress experienced in demanding situations (Bandura, 1989). Webster-Stratton (1990), in a review of factors affecting parental stress, stated that public displays of problem behaviour increase parental stress beyond the levels felt by parents at disruptive

behaviour generally. This heightened stress may negatively bias parents' perception of their children. This could therefore bias attributions for the behaviour and lead to behavioural responses that could be counterproductive. In a study of parents of offspring with severe mental illness, Pickett, Greenley and Greenberg (1995) found that the fear of stigma contributed to subjective distress, and these parents may be more fearful of stigma if their offsprings' difficult behaviour occurred publicly. Mash and Johnston (1990) reviewed the determinants of parenting stress in families of hyperactive and physically abused children and concluded that child characteristics (such as problem behaviour) and environmental characteristics (such as the immediate context of the interaction) combine to influence parent-child interactions and contribute to parental distress through affecting parental cognitions and perceptions. The authors stated that the existence of the usual parental positive attributional bias does not guarantee that parents will think and act in accordance with this belief in all situations. This suggests that the effect of context needs exploration in carers of people with ID and SIB.

Parents are struggling to manage incidents of SIB and this has an effect on their well-being which impacts on the quality of life for their offspring through reduced interactions and the possibility of neglect and abuse. This may suggest an area of intervention – attribution shift for parents. This is an under-researched area rich in meaning therefore there is a need for work investigating parents' naturally-occurring attributions and how this affects outcome.

## **Aims and Hypotheses**

### **a) Aims**

The initial aim of the study is to examine the variety of attributions parents make about their child's self-injurious behaviour. The study will further investigate the meaning of the event for the parents, and how this impacts on feelings of self-efficacy

and the level of stress experienced by the parents. Additionally, the work will explore how these factors are affected by incidents of SIB in public and private contexts.

## **b) Hypotheses**

The hypotheses are theoretically rather than empirically driven and are:

1. that parents will have a variety of causal explanations for their offsprings' SIB.
2. that these attributions will correlate with feelings of self-efficacy as a parent and level of stress experienced in managing incidents of SIB, e.g. attributions internal to the parent (self-blame) will produce low self-efficacy beliefs and the parent will experience increased stress in managing the incident, and that attributions of SIB being solely attributable to diagnosis will produce higher feelings of self-efficacy and less stress responses.
3. that attributions, self-efficacy and stress will be affected by the context in which they occur, as determined by qualitative analysis.

## **Plan of Investigation**

### **a) Participants**

As the prevalence of SIB is associated with more severe ID and younger individuals, this would require the identification of adults aged between 16 and 40 with 'severe/profound' ID who exhibit SIB and live within the Argyll and Clyde area. This would involve approaching Community Learning Disability Teams (CLDTs) and voluntary organisations for initial identification. As parental gender differences have previously been reported in family research on disability (e.g. Roach et al 1999), biological mothers would be approached via the CLDT or voluntary organisation and invited to participate. Mothers would only be included if they had significant input into their child's care, and their child had a significant problem of SIB.

## **b) Recruitment**

Recruitment of participants would require the identification of individuals with ID who exhibit SIB within the Argyll and Clyde area, in order to invite their mothers to participate. Initial approach would be through the CLDT or voluntary organisation. Prior written consent from all participants (the mothers) would be obtained. It would be emphasised that the interview would serve as an opportunity to discuss their experiences of SIB in a supportive context.

## **c) Design and Procedures**

This study uses a method which extracts categorical data about the nature of people's attributions from their narratives. These narratives provide a rich source of data for a secondary qualitative analysis, exploring other aspects of meaning which the mothers ascribe to their offspring's SIB. A qualitative approach allows for the examination of patterns and themes emerging from these attributions in order to do this. However, the underlying aim is to examine the relevance of these attributions for mothers. Using a quantitative method of analysis for this aspect allows for the associations of ratings on attributional dimensions and measures of self-efficacy and stress to be explored. Previous studies exploring the impact of attributions have also combined different methodologies (e.g. Boyle, 2003; Barrowclough, Johnston & Tarrier 1994).

The design and implementation of the study is guided by Elliot, Fischer and Rennie's (1999) guidelines for qualitative research in psychology. These guidelines also outline commonalities in qualitative and quantitative approaches, namely explicit scientific context and purpose, using appropriate methods and contributing to the knowledge base. These will also be applied to ensure the standard of the quantitative aspect of the study.

### *Development of Semi-Structured Interviews*

The content of the semi-structured interviews will be determined through a two-stage process.

Initially, focus groups would be conducted with mothers of individuals with ID who exhibit SIB. These would take the form of asking them to recall and reflect upon their own experiences of SIB in their offspring in both public and private contexts. The format for this would be a semi-structured discussion with the aim of exploring:

1. the types of spontaneous attributions that mothers make and themes emerging from them.
2. other issues arising from the discussion which appear relevant to the topics of interest and therefore require further exploration.

The format and topics of interest can be found in Appendix 3.2.

With the consent of the participants, the discussion would be recorded and transcribed verbatim. This discussion would simply serve as a basis to generate the interview schedule to be used in the main study and data from the focus groups would not be analysed.

Following this, the second stage would be implemented. The interview schedule based on the focus group work would then be piloted with a small number of participants to ensure that the necessary attributions can be extracted before being used in the main study. Whilst the interviews will be semi-structured, it is necessary to gain an understanding of the issues that need to be covered in order to generate an appropriate dialogue for analysis.

After development and piloting, the main phase of the study will be initiated. Written informed consent would be obtained from all participants and standard information would be given at the start of the interview, that they can receive information on the outcome of the work on its completion, that they can withdraw at any time and that all



information would be kept anonymous and confidential. Interviews would be recorded and participants given an identification code. Participants would also complete two formal measures, detailed below.

#### **d) Measures**

Basic participant information would be gathered at the start of the interview. This allows for the investigation of the characteristics of the group and meeting Elliot et al.'s (1999) guidelines for 'situating the sample'. This information would include:

1. Parent information – age, sex, marital status, occupation, supports available.
2. Offspring information – age, sex, diagnosis (if any), level of communication, frequency, severity and type of SIB.

#### *Semi-structured interview*

Elliot et al. (1999) state that qualitative research lends itself to understanding participants' perspectives and defining phenomena in terms of experienced meanings and contributes to a process of revision and enrichment of understanding, rather than verifying earlier conclusions or theory. Elig and Frieze (1979) recommend open-ended procedures for the researcher who is asking for causal attributions in under-researched areas. A structured format restricts responses whereas open-ended formats enable the researcher to gain a true reflection of the extent and type of attributions that mothers make.

The areas covered in the interview will be guided by the responses generated in the focus groups and may include perceived causes of SIB, responses to it, feelings of self-efficacy and stress in different contexts along with any other topics of interest.

Strauss and Corbin (1998) state that qualitative data collection and analysis involves the interplay between the research and the researcher and according to Elliot et al.'s

(1999) guideline of 'owning one's perspective', the background and influence of the researcher needs to be acknowledged and examined.

Formal measures will also be included to tap into the factors outlined in the hypotheses, namely feelings of self-efficacy and stress, and also to describe the characteristics of the participant group. These will include:

1. The Parenting Stress Index (3<sup>rd</sup> Edition, Abidin 1995). The PSI is a 101-item self-report questionnaire designed to identify parent and child characteristics that contribute to parenting stress and which may place the family at risk of development of dysfunctional parenting. There are five response categories ("strongly agree" to "strongly disagree"), with higher scores indicating higher parenting stress. Although it is only normed for children up to 12 years, it is specifically designed to investigate stress in parents, which general stress measures fail to do. Abidin (1995) cites Cronbach's alpha of 0.93 for total parent domain and 0.90 for the total child domain.
2. Measure of parents' self-efficacy (Hastings & Brown 2002). Bandura (1997) strongly recommends development of more specific rather than general self-efficacy measures thus this domain-specific measure of parents' perception of efficacy in relation to their child's behaviour problems was created. The scale contains five items: feelings of confidence, control and satisfaction, perception of positive impact and a rating of how difficult they find it to manage the behaviour. Each is rated on a 7-point scale. Although few psychometric data are available, Hastings and Brown (2002) found it have an excellent level of internal consistency, reporting Cronbach's alpha for mothers as 0.94.

These measures would be administered at the end of the interview.

#### **e) Settings and Equipment**

Participants would be seen in a setting that was comfortable for them whilst ensuring the researcher's safety. This may be in the offices of the local CLDT. Equipment required includes a tape recorder, tapes, transcription machine and copies of the formal assessments. Equipment is available from the Department of Psychological Medicine on request.

#### **f) Power Calculation**

The initial aspect of the study is qualitative in character and aims to examine the nature and content of mothers' spontaneously generated attributions, in order to extract categorical data for quantitative analysis. It is therefore not appropriate to use a power calculation to determine sample size for this aspect. Furthermore, there is a dearth of previous research on which to base a power calculation. However, the qualitative approach will be combined with a quantitative facet to examine the impact of these attributions on self-efficacy and stress. To achieve this, correlational analyses will be carried out and this therefore does allow a power calculation. A correlation co-efficient of 0.6 would indicate a significant level of association assuming a null hypothesis of 0. Using a one-tailed test with alpha set at 0.05 and power set at 0.8 as per convention, the required sample size is 16 (calculated using the UCLA power calculator). This therefore will be the minimum number of participants recruited into the study.

#### **g) Data Analysis**

Initially, the nature and content of attributions will be explored. Interviews will be fully transcribed to allow analysis of responses. Answers to open-ended questions will be coded on different attributional dimensions in a similar way to that described by Boyle (2003), adapted from Elig and Frieze (1979). This involves rating responses along the relevant attributional dimension and allows for correlational analyses to be carried out. Each attributional dimension is rated on a scale of 1-3, for example for the locus of causality dimension, a rating of 1 means that mothers blame themselves for their

child's SIB, whereas a rating of 3 would mean that an entirely external cause is blamed. This rating requires an independent rater to ensure reliability.

The interviews would also be subjected to content analysis. Dey (1993) states that content analysis involves (1) dividing the data into manageable parts, (2) collecting responses together that relate to the areas of interest, (3) creating categories that describe similar responses within the general areas and (4) combining or dividing categories where data are better described in a rearranged structure. An independent rater is again required to ensure reliability. Illustrative examples will be used to demonstrate patterns within the data and credibility checks provided by consulting an expert in the field (Elliot et al. 1999).

Scores on the formal measures will be subjected to correlational analyses to explore associations between codings for specific dimensions and self-efficacy and stress, for example associations between parenting competence in public settings and ratings of locus of cause dimension would be examined using correlation.

### **Practical Applications**

The attributions that mothers make in the face of SIB may impact on their emotional well-being and subsequently on parent-offspring interactions. Parental stress has been repeatedly linked to negative effects on caregiving including neglect and abuse (Halpern, 1993). Negative attributions may negatively affect perceptions of the offspring and thus interactions (Mash & Johnston, 1990).

This research should help identify types of attributions that are potentially unhelpful to mothers in influencing self-efficacy and stress. Attributions may be amenable to modification (e.g. Wilson & Linville, 1985) and self-efficacy generally appears to be a construct that is alterable at a practical level (Bandura, 1989). This would suggest

the possibility of interventions to address these factors which would be of benefit to both the mother and the individual with ID.

### **Timescale**

January 2005: Submission of outline proposal

January-March 2005: Revisions to proposal

March 2005: Submission of approved proposal

April/May 2005: Submission to Ethics Committee

September 2005: Ethical approval obtained

October 2005: Pilot Phase – Focus Groups conducted

November-April: Data collection for 6 months

May-July 2006: Analysis and write-up

### **Ethical Approval**

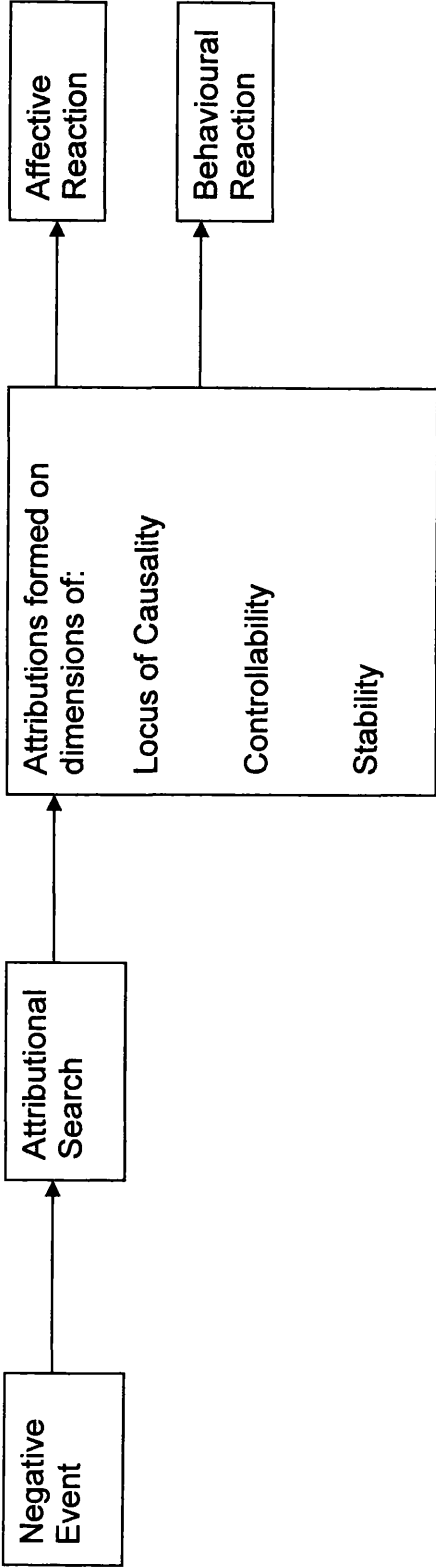
Ethical approval would be sought from the Local Research Ethics Committee relating to Argyll and Clyde Health Board.

Information sheets and consent forms would be produced for the participants in the focus group and main study phases.

As the subject matter is by its very nature emotive and potentially distressing, the purpose of the study would be carefully explained to all participants prior to interview and a full debriefing would be conducted subsequently. Anonymity and confidentiality would be emphasised and ensured.



Figure 1. A model of the attributional process based on Weiner (1980)



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## **Amendments to Proposal**

Following Ethical approval, two substantial amendments to the protocol were made.

The first arose out of concern about recruitment from a very small and specific population, and the depleting effect on this population that running a focus group would have. If the focus group were run, this would mean that those 4 to 6 participants would then be lost to the main interview study, as including them would confound the data.

The revised plan was to drop the focus group and conduct pilot interviews with 2 individuals. Content analysis was then conducted on the transcripts, in order to pick out the main themes and using these to drive the interview schedule. The principal effect of this amendment was to change how the interview schedule was devised, in an attempt to preserve the numbers of potential participants available to the main study from a small but important population.

The second amendment involved reducing the lower age limit of the offspring with intellectual disabilities and self-injurious behaviour from 16 to 12. The rationale for this was based on feedback from the agencies assisting in recruitment, who felt that the original age limit was restrictive. Those agencies that assisted in recruitment indicated that the issue under investigation was of considerable importance to the parents of this younger age group.

The geographical area from which recruitment took place was also expanded, although ethical approval was not required for this as participants were sought from the non-NHS voluntary sector.

## **Chapter 4**

### **Major Research Project Paper**

**An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.**

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Section of Psychological Medicine

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[Prepared in accordance with guidelines for *British Journal of Clinical Psychology*

(see Appendix 4.1)]



**TITLE:** An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.

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## **ABSTRACT**

**OBJECTIVES:** Although self injurious behaviour (SIB) is recognised as one of the most difficult management problems in people with intellectual disabilities (ID), the way that mothers attempt to make sense of the behaviour has been largely ignored. However, in parents of other groups of offspring, attributions and cognitions have been shown to predict maternal well-being and engagement in treatment.

**DESIGN:** A mixed methods (quantitative & qualitative) design was employed.

**METHODS:** Using Weiner's (1980) attributional model, 13 mothers were interviewed to examine the nature and content of their views about their offsprings' SIB, using semi-structured interviews and measures of parenting self-efficacy and stress.

**RESULTS:** The findings suggested that mothers made a diverse and complex range of attributions that were consistent with attributional dimensions of locus of cause, stability and controllability. The nature of their attributions reflected their feelings of pessimism regarding the possibility of change and their often contradictory views about causes of SIB and consequent difficulties with interventions.

**CONCLUSIONS:** Taking account of mothers' views will better enable professionals to provide adequate support to these families.

## INTRODUCTION

Self-injurious behaviour (SIB) has been defined by Murphy and Wilson (1985, p15) as:

*'Any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm (includes) bruising, lacerations, bleeding, bone fractures and breakages, and other tissue damage'.*

Wisely et al. (2002) have stated that SIB presents as one of the most difficult management problems in people with intellectual disabilities (ID). It is by definition harmful to the individual and impacts on wellbeing and quality of life. Furthermore it causes great distress in those people caring for them, and as Oliver and Petty (2002) state, poses significant challenges to clinicians. A review of SIB by Halliday and Mackrell (1998) reported prevalence rates of between 4 and 10% of people with ID exhibit SIB and approximately 90% of those with SIB have severe or profound ID (Oliver et al., 1987). Self injurious behaviour is associated with some genetic conditions such as Lesch-Nyhan syndrome, Cornelia de Lange syndrome and neurological conditions such as frontal lobe epilepsy (Cataldo & Harris 1982). Many people who engage in SIB do so in more than one way and engage in other types of challenging behaviour (Emerson 1990, Borthwick-Duffy 1994). Younger adults and children are more at risk of exhibiting SIB, and prevalence rates are generally higher for males than females and for people who are non-verbal or have communication problems, sensory impairments, experience particular environmental disadvantage or have a dual diagnosis (Murphy & Wilson 1985, Borthwick-Duffy 1994). Self injurious behaviour is qualitatively different from other forms of challenging behaviour, especially for parents faced with their offspring harming themselves and struggling to understand and manage it.

Parents' causal explanations for self-injurious behaviour exhibited by their offspring with intellectual disability is an under-researched area. Attribution theory outlines the need humans have to seek explanations for events (Heider, 1958) and suggests that the ways in which parents interpret their offsprings' self-injurious behaviour (SIB) may be a crucial process in determining how parents react both emotionally and practically. Wong and Weiner (1981) suggest that people engage in attributional search following negative or unexpected events, under which heading self-injurious behaviour could be placed. Attribution theorists assume that individuals use causal explanations to understand, control and master their environment (Forsterling, 1988). Attributions may influence parents' emotional well-being and sense of efficacy and may impair their ability to interact optimally with their offspring, thus leading to poor management of the incident of self-injurious behaviour. Within the field of attributional research, there are several models which may provide insight into parents' reactions to their offspring's self-injurious behaviour. Weiner's (1980) model has been commonly used in the field of challenging behaviour. This model outlines three attributional dimensions that affect emotional responses and subsequent behaviour: 1) locus of causality (whether the cause resides within the person or the external world), 2) controllability (whether it is subject to personal influence) and 3) stability (whether the cause is likely to change). This is set out graphically in Figure 1. According to the model, attributions of controllability or stability determine the emotional reactions of the observer and consequently increase or reduce the possibility of the observer offering help. Therefore, the model would predict that an observer will be more sympathetic and helpful if the cause of the behaviour is seen as outwith the person's control (such as due to epilepsy) and more angry and less likely to help if the cause of the behaviour is seen as within their control (such as perceiving them as 'doing it for effect'). Attributions of stability (where the cause is perceived as being unlikely to be amenable to change) would be associated with reduced feelings of optimism for change, and less helping behaviour.

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FIGURE 1 ABOUT HERE  
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One potential limitation to applying attributional theory to parents of offspring with severe ID is that they may view the behaviour as outwith their offspring's control, thus producing little attributional variability. However, research on families of people with schizophrenia has shown that an attributional model may be useful even where behaviour may be expected to be attributed to a specific cause (Barrowclough, Johnston & Tarrier, 1994). Chavira et al. (2000) have investigated mothers' attributions and emotions regarding the problem behaviours of children with developmental disabilities and provided support for an attributional framework. Parental causal explanations for challenging behaviour have been examined specifically in Cornelia de Lange syndrome, particularly associated with SIB (Hyman & Oliver 2001). This showed that parents made a variety of causal explanations regarding the influence of the syndrome on behaviour. This appears to be the only study examining parents' causal explanations for SIB. Allen (1999) has highlighted the need for more research on parents, as much of the work in this area has been conducted on staff groups (e.g. Hastings & Remington 1994, 1995; Bromley & Emerson 1995; Hastings et al. 1995, 1997; Dagnan et al. 1998; Stanley & Standen 2000; Mossman et al. 2002; Jones & Hastings 2003). Hassall and Rose (2005) have stated that although parental attributions and cognitions have been substantially investigated in parents of other groups of offspring, there has been a dearth of such work in parents of offspring with intellectual disabilities, despite the fact that it is warranted.

Joiner and Wagner (1996) have argued that attributions can lead parents to make negative self-evaluations regarding their parenting skills. These negative self-evaluations may make a parent feel helpless, overwhelmed and incompetent. If parents make attributions internal to the self (self-blame) or perceive increased responsibility for events, this is likely to reduce feelings of self-efficacy and increase stress. Self-efficacy has been identified as a key factor in terms of its relationship to a number of outcomes, including parenting stress (see Coleman & Karraker, 1997, for a review). Bandura (1989) suggests that individuals anticipate failure when they are overwhelmed by aversive physiological arousal. Feelings of self-efficacy depend on how the situation is appraised and parents may find public displays of SIB more distressing. Low maternal self-efficacy is correlated with high levels of maternal stress (Wells-Parker et al. 1990).

However, attributions may not be fixed and self-efficacy is likely to vary for different behaviours in different contexts (Bandura, 1989). Drawing on the field of wider developmental and family relations literature introduces the notion of the immediate context of behaviour affecting carers' cognitions and thus perhaps their behavioural responses. Belief in one's capacity to parent is likely to affect the level of stress experienced in demanding situations (Bandura, 1989). Webster-Stratton (1990), in a review of factors affecting parental stress, stated that public displays of problem behaviour increase parental stress beyond the levels felt by parents at disruptive behaviour generally. This heightened stress may negatively bias parents' perception of their children. This could therefore bias attributions for the behaviour and lead to behavioural responses that could be counterproductive. In a study of parents of offspring with severe mental illness, Pickett, Greenley and Greenberg (1995) found that the fear of stigma contributed to subjective distress, and these parents may be more fearful of stigma if their offsprings' difficult behaviour occurred publicly. Mash and Johnston (1990) reviewed the determinants of parenting stress in families of

hyperactive and physically abused children and concluded that child characteristics (such as problem behaviour) and environmental characteristics (such as the immediate context of the interaction) combine to influence parent-child interactions and contribute to parental distress through affecting parental cognitions and perceptions. The authors stated that the existence of the usual parental positive attributional bias does not guarantee that parents will think and act in accordance with this belief in all situations. This suggests that the effect of context needs exploration in carers of people with ID and SIB.

Parents are struggling to manage incidents of SIB and this has an effect on their well-being which impacts on the quality of life for their offspring through reduced interactions and the possibility of neglect and abuse. Parental cognitions such as attributions may also affect how acceptable they find interventions aimed at reducing SIB, as the rationale may contradict parental understanding of the problem and mean that they are less likely to take professional advice, making interventions less effective (Hassall & Rose 2005). This may suggest an area of intervention – attribution shift for parents. This is an under-researched area rich in meaning therefore there is a need for work investigating parents' naturally-occurring attributions and how they affect outcome.

The initial aim of the study was to examine the variety of attributions parents make about their child's self-injurious behaviour. The study further investigated the meaning of the event for the parents, and how this impacted on feelings of self-efficacy and the level of stress experienced by the parents. Additionally, the work explored how these factors were affected by incidents of SIB in public and private contexts. The hypotheses were theoretically rather than empirically driven and were that parents would report a variety of causal explanations for their offsprings' SIB and that these attributions would correlate with feelings of self-efficacy as a parent, and the level of stress experienced in managing incidents of SIB. It was hypothesised that attributions of controllability would be associated with self-efficacy in that mothers how saw the behaviour as under their offsprings' control would experience low self-efficacy; also, attributions of stability would be associated with stress in that mothers who saw their offsprings' SIB as stable and chronic would experience increased stress and burnout. Finally, it was hypothesised that attributions, self-efficacy and stress would be affected by the context (e.g. public versus private) in which they occurred, as determined by qualitative analysis.



## **METHODS**

### *Participants*

For both the pilot and main phases of the study, a convenience sample was recruited. Initial attempts to recruit through statutory services proved fruitless despite early assurances, suggesting that they do not have an adequate working relationship with these mothers. Consequently the majority of the sample was recruited through voluntary organisations, involving liaising with their workers across Scotland. Considerable effort was expended to recruit from this small and hard to reach population.

The prevalence of SIB is associated with more severe ID and younger individuals, therefore people aged between 12 and 40 with 'severe/profound' ID who exhibited SIB were identified. As parental gender differences have previously been reported in family research on disability (e.g. Roach et al 1999), biological mothers were approached. Mothers were included if they had significant input into their child's care, and their child had a significant problem of SIB. Prior written consent from all participants (the mothers) was obtained. The decision about the level of ID experienced by the offspring was made by the agencies assisting with recruitment. As initial identification and approach was through a third party, it is unclear exactly how many mothers were invited to participate. However, of those contacts passed to the investigator, 13 agreed to participate and 3 refused. Reasons for refusal included family bereavement and concerns about possible identification. A further 2 potential participants were excluded as their offspring did not have significant SIB.

### *Demographic characteristics*

Demographic data collected included age, gender, level of communication and type and frequency of SIB of the offspring and age, marital and work status of the mother. This allowed for the investigation of the characteristics of the group and meeting

Elliot et al.'s (1999) guidelines for 'situating the sample'. Offsprings' ages ranged from 12 to 37 years (mean 20.69, SD 9.16). Eleven of the offspring were male. Eight offspring had no verbal communication. Types of SIB included scratching, hand biting, nipping, head banging, skin picking and slapping and these were generally severe and very frequent. Six offspring engaged in multiple types of SIB, and 3 individuals bit themselves, two slapped themselves, one person hit their head and a further person nipped herself. All of the offspring engaged in SIB on at least a daily basis.

The mothers' ages ranged from 32 to 63 (mean 47.23, SD 9.3). Eight of the mothers were married or cohabiting. Of the single mothers, 2 were divorced or separated, two had never married and one was widowed. Nine of the mothers were fully occupied with domestic tasks and caring from their offspring. Two mothers were in full-time employment and 2 others were in part time employment.

## **Measures**

This study used a method which extracts categorical data about the nature of people's attributions from their narratives. These narratives provide a rich source of data for a secondary qualitative analysis, exploring other aspects of meaning which the mothers ascribe to their offspring's SIB. A qualitative approach allowed for the examination of patterns and themes emerging from these attributions in order to do this. However, the underlying aim was to examine the relevance of these attributions for mothers. Using a quantitative method of analysis for this aspect allowed for the associations of ratings on attributional dimensions and measures of self-efficacy and stress to be explored. The strength of the mixed quantitative and qualitative approach allowed the meaning underlying the simple associations to be explored.

Previous studies exploring the impact of attributions have also combined different methodologies (e.g. Boyle, 2003; Barrowclough, Johnston & Tarrier 1994).

### *Development of Semi-Structured Interviews*

The content of the semi-structured interviews was determined through a two-stage process.

Initially, two pilot interviews were conducted with mothers of individuals with ID who exhibited SIB. These took the form of asking them to recall and reflect upon their own experiences of SIB in their offspring in both public and private contexts. This involved facilitating a dialogue and enabling them to talk freely about their experiences of parenting in a non-judgemental fashion. With the consent of each of the participants, the interview was recorded and transcribed verbatim. Content analysis was conducted on the transcripts, in order to pick out the main themes and these were used to develop the interview schedule (Crabtree & Miller 1992). This process is described more fully in Appendix 4.9.

### *Semi-structured interview*

Elliot et al. (1999) state that qualitative research lends itself to understanding participants' perspectives and defining phenomena in terms of experienced meanings and contributes to a process of revision and enrichment of understanding, rather than verifying earlier conclusions or theory. Elig and Frieze (1979) recommend open-ended procedures for the researcher who is asking for causal attributions in under-researched areas. A structured format restricts responses whereas open-ended formats allow the participants to present more expansive and complex views, providing a better insight into the nature of mothers' attributions.

The areas covered in the interview were guided by the themes derived from the pilot interviews and included perceived causes of SIB, responses to it and feelings of self-efficacy and stress in different contexts.

### *Formal Measures*

Formal measures were administered in relation to the hypotheses predicting links between specific attributional dimensions and mothers' sense of efficacy and stress,. These formal measures also provided greater understanding of the characteristics of the participant group. These measures were as follows:

1. The Parenting Stress Index (3<sup>rd</sup> Edition, Abidin 1995). The PSI is a 101-item self-report questionnaire designed to identify parent and child characteristics that contribute to parenting stress and which may place the family at risk of development of dysfunctional parenting. There are five response categories ("strongly agree" to "strongly disagree"), with higher scores indicating higher parenting stress. Although it is only normed for children up to 12 years, it is specifically designed to investigate stress in parents, which general stress measures fail to do. Abidin (1995) cites Cronbach's alpha of 0.93 for total parent domain and 0.90 for the total child domain, suggesting good reliability and validity.
2. Measure of parents' self-efficacy (Hastings & Brown 2002). Bandura (1997) strongly recommends development of more specific rather than general self-efficacy measures thus this domain-specific measure of parents' perception of efficacy in relation to their child's behaviour problems was created. The scale contains five items: feelings of confidence, control and satisfaction, perception of positive impact and a rating of how difficult they find it to manage the behaviour. Each is rated on a 7-point scale. Although few psychometric data

are available, Hastings and Brown (2002) found it to have an excellent level of internal consistency, reporting Cronbach's alpha for mothers as 0.94.

The initial aspect of the study was qualitative in character and aimed to examine the nature and content of mothers' spontaneously generated attributions, in order to extract categorical data for quantitative analysis. It was therefore not appropriate to use a power calculation to determine sample size for this aspect. Furthermore, there is a dearth of previous research on which to base a power calculation. However, the qualitative approach was combined with a quantitative facet to examine the impact of these attributions on self-efficacy and stress. To achieve this, correlational analyses were carried out and this therefore did allow a power calculation. A correlation coefficient of 0.6 would indicate a significant level of association assuming a null hypothesis of 0. Using a one-tailed test with alpha set at 0.05, a sample size of 16 was required to reach power set at 0.8 as per convention. However, given the difficulties encountered during recruitment, the sample size of 13 with the same parameters gives a power of 0.69 (calculated using the UCLA power calculator).

## **Procedure**

After initial pilot work to develop the semi-structured interview, the main phase of the study was initiated. Interviews were face to face and conducted in a setting that was comfortable for the participants whilst ensuring the researcher's safety. Written informed consent was obtained from all mothers and standard information was given at the start of the interview, that they could receive information on the outcome of the work on its completion, that they could withdraw at any time and that all information would be kept anonymous and confidential. Interviews were recorded and participants given an identification code. Participants also completed the two formal measures. This process took on average around one and a half hours.

**Strategy for analysis**

Initially, the nature and content of attributions were explored. Interviews were transcribed verbatim to allow analysis of responses, a process taking approximately 3-4 hours per transcript. Answers to open-ended questions were coded on attributional dimensions following the process described by Boyle (2003), adapted from Elig and Frieze (1977), in order to explore hypothesised links to the formal measures. The first step was to identify interview discourse relating to the three attributional dimensions of 1.) causality, 2.) stability and 3.) controllability, adapted from Weiner (1980). The adapted coding scheme was then used to obtain a rating on locus of cause, stability and controllability from the narratives. Each was rated on a scale of 1 to 3. Scores of 1 were given a pole of each dimension (internal, stable, controllable) and a score of 3 to the opposite pole (external, uncontrollable, unstable). Scores of 2 were given for single attributions that evoked both ends of a single dimension or an interaction of each pole. Coding of a sample of transcripts by a second independent rater indicated a reasonable level of inter-rater reliability (percentage agreement .76, Neuendorf 2002). Cohen's kappa was not used because the second rater was asked to both identify and rate attributions. Where there was disagreement, this was resolved by discussion. The criteria for selecting data from transcripts are described in Table 1.

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TABLE 1 ABOUT HERE  
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Scores on the formal measures were subjected to correlational analyses to explore associations between codings for specific dimensions and self-efficacy and stress. Relationships between continuous variables that were not normally distributed were examined by rank-order correlations.

## RESULTS

The results are presented in two sections, relating to quantitative and qualitative data. The quantitative data section will first report the descriptive statistics for the formal measures. This will serve to 'situate the sample' in accordance with Elliott et al.'s (1999) guidelines for qualitative research. Following this, the correlational analyses examining the associations between the attributions and perceived parenting self-efficacy and stress will be reported. The qualitative findings regarding the nature and content of the attributions and the implications thereof will then be presented.

### 1. Sample characteristics

#### a) Feelings of self efficacy (Parenting Self Efficacy Scale)

Table 2 shows that the mean score on this scale was 17.69 (SD = 7.49). The range of scores was 9-30, suggesting that there was variability in perceived levels of self-efficacy in dealing with SIB. On closer examination of responses, items that commonly received low scores indicative of lower feelings of self efficacy were finding it personally difficult to deal with SIB, and feeling in control of offspring's SIB.

#### b) Maternal stress levels (scores on the Parenting Stress Index)

Consistent with previous research findings (e.g. Rodrigue et al. 1990; Roach et al, 1999), the average total parental stress score (mean = 319.15, SD = 35.94, range 238-374) fell into the significant range compared to norms of parents of normally developing children. Twelve mothers had overall stress levels that were significant. On the child domain, twelve mothers rated their offspring's characteristics to cause them significant levels of stress. A number of mothers (n=8) had significant levels of stress on the parent domain. However, these findings should be interpreted with some caution as norms only exist for parents of offspring aged up to 12.

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TABLE 2 ABOUT HERE  
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## **2. Associations of attributions with mothers' feelings of self efficacy and stress**

Associations between the attribution ratings and scores from the standardised measures were investigated. Due to the nature of the data, mothers often reported multiple, conflicting attributions, so the first response for each dimension was used for these analyses, which are displayed in Table 3.

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TABLE 3 ABOUT HERE  
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The only significant association found was between parenting self-efficacy and attributions regarding controllability. This was in the opposite direction to that predicted, as mothers who felt that their offsprings' SIB was under their personal control had lower feelings of self-efficacy. The hypothesised association between stable attributions and high stress was not found.

## **3. Content analysis**

Findings from the content analysis of transcript data are presented. The qualitative analysis provided deeper insight into the nature of attributions made by mothers in relation to the dimensions of locus of cause, stability and controllability. The meanings of these patterns were explored through examining the implications for affective responses and perceptions about the dimensions, and the effect of context (public versus private) was further examined. The number of mothers generating particular patterns is indicated in the text. The nature and patterns of attributions are



grounded by illustrative examples in the text as per Elliott et al's (1999) guidelines.

Fuller examples of narrative are appended (see Appendices 4.10 & 4.11).

### **A. Locus of cause**

All mothers had theorised about the causes of their offspring's self injurious behaviour. Possible causes included offspring's anger or frustration, sensory stimulation, attention seeking, noise and maternal behaviours. All mothers gave multiple attributions relating to locus of cause, often contradicting earlier comments. These contradictions inherent in the nature of the discourse are reflected in the analysis. Due to the contradictory nature of the narratives, implications did not follow seamlessly from initial attributions.

#### ***A.i. Internal Locus***

As an initial attribution, one mother blamed herself and this was given as a subsequent attribution by 6 other mothers. The mother who blamed herself initially reported a generalised feeling of guilt, rather than specific behaviour. Those mothers who reported feeling subsequently that they could cause their offspring's SIB mentioned specific behaviours or incidents.

*"I can cause the biting of the hand and that is when he wants to do that with his mouth and I keep putting his hand down. He'll get angry then and get the other hand and bite the other hand".*

Six mothers believed the cause of their offspring's SIB to be internal to the offspring in their initial attribution, and all mothers did so in subsequent attributions. Commonly cited causes included reactions to frustration or expression of negative emotion, changes to routine or for 'effect'. Other reasons given by the mothers included sensory stimulation or communication of illness.

*"now I just think it's stress, boredom, ....determination to annoy his parents, sometimes. It's just his way of expressing himself."*

### **A.ii. External Locus**

One mother blamed external causes as an initial attribution, explaining that she felt the changing care team around her son contributed to his behaviour.

*"I do think that having so many people, I mean I must have had 100 people, was something that was maybe a catalyst in [offspring]'s self injury".*

Nine of the mothers speculated about external causes as subsequent attributions.

Such causes included environmental transitions, noise and family stress.

*"The transitions, going from one place to another, they can be triggers, so maybe that's something to do with that. To do with environment and changing".*

A number of mothers expressed difficulty in adhering to advice given to them by professionals, often behavioural interventions from psychologists (n = 6). This appeared to be because they felt that the rationale behind, for example, planned ignoring, did not correspond to their own beliefs about the cause of the SIB:

*"I had a lot of problems with a lot of the stuff, about, you know, planned ignoring and all this kind of thing. For me, I just see the self injury, I never felt the feeling that he's doing it for attention, it was more to do with how he was feeling and how he was reacting and ignoring it just, ... he could do so much damage I just felt I couldn't".*

### **A.iii. Mixed Locus**

Many of the mothers had speculated about numerous possible causes and were unable to attribute SIB to one source in the first instance (n = 6), and eight mothers felt unable to do so subsequently, often after having attributed cause in the first instance.

*"And in my opinion, it might be because of a lack of communication, it might be a boredom thing, it might be frustration, it might be because she's upset or sad. Got a period, who knows. We haven't actually come up with any hard and fast reasons for why it might be, I'm sure there are lots and lots of reasons, it might be because there's not enough going on in her head, I don't know."*

Related to this, many of the mothers (n = 9) expressed a lack of understanding regarding cause, and this led to feelings of a need to search for meaning and to 'fix it', accompanied often by feelings of sympathy for their offspring:

*"I think really you feel so helpless, because I can't figure it out. That to me is my ultimate aim. It's an ultimate aim that I know I might never achieve, but it is my ultimate aim to work it out. I don't think any of us should stop, we should always be searching. To me, it's our failing that we're not able to figure it out. I know how totally impossible it can be, if the child can't communicate to you, then....I do see it as not just my failure but all our failure".*

#### **A.iv. Context**

Several of the mothers (n = 4) found that incidences of SIB occurring in public were particularly difficult, as although the causes were probably the same as those in private, public attitudes were unhelpful as a result of their views.

*"He's always looking for an audience and people'll come and try and help and then that's exactly what he's getting and it escalates then. It can make you hostile towards people, you tell them to just go away, to just leave me. The more people that's there, the more it'll go on".*

#### **B. Stability**

The qualitative findings indicate that mothers tended to be more consistent in their attributions of the stability of causes for their offspring's SIB, and for the stability of the SIB over time.

##### **B.i. Stable Locus**

The clearest finding to come out of the examination of the data was a degree of pessimism or belief that the SIB was chronic and thus stable. Seven of the mothers gave this view as their initial attribution and a further four subsequently.

*“ we’ve explored absolutely every avenue to find out if there’s anything we can do or how to, er, we’ve consulted psychologists and worked on behaviour modification programmes and so forth, and at the end of the day, it’s doesn’t make the slightest bit of difference”.*

The majority of mothers (n = 11) expressed some form of negative emotion in response to the constant nature of the SIB, which corresponded with the general air of pessimism regarding change. These feelings were generally of frustration and helplessness, expressed as feelings of being pushed to the limits:

*“I’ve got to become absolute love, to be able to deal with [offspring]. That’s, people might think, oh she’s a saint or something, ... that’s what I believe. That’s the only way I can say it because that’s the extremity of what I’d had to cope with. Because I know I’ve been totally, I’ll tell you the truth, it wouldn’t bother me if I was to die tomorrow, it wouldn’t bother me, but I don’t want to stop caring for [offspring], they’re my life, that’s the only reason I’ve got now, I’ve got no life, I don’t know what’s going on out there in the world, I’m not part of the world, I can’t be”.*

Other mothers (n = 5) expressed concerns about the future. One mother expressed fears that her offspring’s SIB could develop into physical aggression towards other people. Others speculated about difficulties with the future placement of their offspring if the SIB persisted.

*“I don’t know what to do with her, for it to work. Should I try and find out what’s happening about a placement? That worries me and all, because I’ve had her all this time and you feel like you’re just palming her off to somebody else”.*

### ***B.ii. Unstable***

Only one mother expressed the view that her offspring’s SIB would improve as an initial attribution and a further 3 expressed similar views, or viewed the cause of their offspring’s SIB as being unstable and unpredictable as subsequent attributions.

*I’ve learned to get to know [offspring] better, and other people, so I’ve had to change too, and other people are learning, how to get to understand [offspring] rather than trying to get him to change. Because of these things and that his health has*

*improved, that's made a big difference to his self injury... which all helps him to cope with his behaviour and helps him not self injure.*

Three of the mothers expressed views outlining the stress they experienced as a consequence of the unpredictability of their offspring's self injurious behaviour.

*"I start crying, you know. I need somebody here, even when he's having a good day, because you don't know, it's that unpredictable. You don't know if he's going to start hurting himself and the moment he does, there's the churning in my stomach, because of that feeling that you can't stop it."*

### **B.iii. Mixed**

Several of the mothers had mixed views about stability, in that they appeared to believe that some change was possible and that their offspring's behaviour might improve, but that the SIB was unlikely to stop completely. Five mothers stated as their initial attributions that they thought that the degree of their offspring's SIB was improving.

*"there's no way it's really gone, and it might never go. But it seems controlled and he's managing to cope with it better".*

A further 3 mothers indicated that they believed progress with SIB could be made, or that the causes of their offspring's SIB varied.

As a consequence of this, several of the mothers (n=6) expressed views about the effectiveness of the intervention methods they used for dealing with their offsprings' SIB. Their view was that these methods were effective in the short term, but not helpful in stopping the behaviour occurring in general and that if more effective methods were available to them, the behaviour would change.

*You just think, "I'm getting nowhere here". I can't help him get himself back into control. So I think that's the worst thing, not being able to help him to stop it. It might just be something he's got to work through. But you can't stand back. So you're back*

*to, your stress levels go way up and helplessness, you just think what can I do for this child to stop him from doing this.*

#### **B.iv. Context**

A fair proportion of mothers felt that context was important in considering the stability of their offspring's SIB. Two of the mothers reported that their offspring never engaged in self injurious behaviour in a public context, and that it was entirely confined to the house. Several (n=7) reported feelings of increased vulnerability when it happened in public, and that they felt themselves and their offspring to be a nuisance.

*"I take [offspring] to the pictures occasionally, and he's maybe starting, and I go to take him out, and as I'm leaving, someone's shouting "mum, what's he doing that for?" All these things. You only hear [offspring], you don't hear all the other kids, even though they're all doing it. You still feel that way, you're a nuisance. You don't feel your contributing to society. You don't. And you don't feel anybody else is making you feel you are".*

#### **C. Controllability**

Mothers expressed a variety of beliefs about who had control over the behaviour or responsibility for intervention. Views were fairly evenly split between responsibility/control resting with the offspring, the mother or external agency or a combination for their initial attributions. However, mothers could express contradictory views about controllability.

##### **C.i. Personal Control of the Offspring**

Three of the mothers stated initially, and a further 10 subsequently, that they felt that the behaviour was under the control of their offspring.

*"she does do half of it to wind me up, because she doesn't do it as much when her dad's here. But the minute he's away to work and I've got her till she goes out, she starts all morning ...I end up giving in to her. I think she plays up a lot to me and she knows I give it her in the end up."*

All the mothers expressed strong affect in their discourses. Where some mothers felt that the behaviour was under the control of their offspring, they expressed negative views about them (n = 5):

*"Sometimes, sometimes you really do hate your child (pause) and sometimes you really do wish your child was dead. I know that's a horrible thing to say but I know I'm sure that other parents of disabled children do feel that. And then that makes you feel guilty because it's your child and you've given birth to him and you do love him. No matter what he does he's your son and you do love him but sometimes you just can't go far enough."*

### **C.ii. Personal Control of the Mothers**

The highest frequency count for attributions of controllability was for those outwith the control of the offspring, or the mother assuming responsibility for controlling or intervening in the behaviour (initial n = 8, subsequent n = 13).

*"Babies crying on the television, I've got to change the programme. Or if he's out I've got to take him away from the noises that's bothering him, he'll settle down then, once he's taken away from what's upset him, he'll settle".*

Mothers who felt it was their responsibility to control the behaviour and support their offspring often expressed views about the unhelpful nature of some of the support they have received (n = 6).

*"When [offsprings]'s bad, the level of support is rubbish because they only want to be there when he's good. When things are bad they run away. He has care from half one till five, and sometimes they go at quarter to two. 'Do you want us to sit here with him?' I just say 'go'. If they can't sustain 20 minutes, they're no use to me sitting there. If I deal with it myself and anybody gets hurt, it's only going to be me. Nobody else. So I feel that easier".*

Six of the mothers expressed views indicative of positive experiences of support in enabling them to deal with their offspring's SIB, either formal or family, although seldom both.

*“they work very, very hard, the staff are very, very caring. It helps me, as I say, I don’t know that I could have [offspring] there if I didn’t know the staff. You know, to me, that takes the stress away. And especially the staff I know really well, who I know know [offspring] really, really well”.*

A further two of the mothers reported feeling that, despite the cause of the SIB, taking control was important to them in feeling that they were supporting their offspring appropriately and in regulating their own feelings of stress in dealing with the behaviour:

*“if I can calm her down, if I can stop her from being miserable, then it’s easy. If she’s calm, I’m calm. If she’s not calm, then I tend not to be. I can be, but sometimes it’s difficult to maintain tranquillity in the face of difficult behaviour”.*

### **C.iii. Mixed**

A further three mothers expressed the view as an initial attribution and 6 as a subsequent attribution that they believed control of the behaviour or responsibility for intervening was shared between themselves and either their offspring or an external agency.

*“I’ve been told to try and ignore it which I can do for a wee while then it drives me absolutely bonkers and I need to go up and tell him to stop it or try and divert, ‘come on we’ll do this, come on we’ll do that’. Sometimes that works and sometimes it doesn’t. And it depends on the mood he’s in, it depends on what I’ve come up with to try and divert him, if it’s diverting enough for him. I find very much it’s all his grounds, if you know what I mean”.*

### **C.iv. Context**

Some mothers felt that context was important in determining control. It was a commonly held view (n = 8) that being in public could hand control of the situation to the offspring, and put the mother under increased pressure to take control of the situation.

*“You just don’t want to escalate things. So you are very very vulnerable outside. I’d much rather be in with him but if ...the care team take him out, I can’t relax, I’m very*



*aware they're going to be on the phone or bringing him back or whatever. So when we're in here, I'm in control; when we're outside, he's in control. I mean, I'm in control of what we're doing or whatever, and he's making it either comfortable or uncomfortable".*

## DISCUSSION

Examining the attributions made by mothers concerning their offsprings' self-injurious behaviour has yielded some key themes that will inform our understanding of their experiences. On the formal measures, this particular group of mothers had moderate perceptions of their parenting efficacy in relation to SIB, although there was considerable variability, and also stress levels were quite high. Hypothesised links between attributions, self-efficacy and stress were either absent or in the opposite direction to that predicted. However, the statistical analyses were underpowered. A notable finding arising from this research is the diverse range of complex attributions mothers made about their offsprings' self-injurious behaviour. All of the mothers had theories about the causes of their offsprings' SIB, and frequently made conflicting attributions about these. The majority of mothers were pessimistic about whether their offsprings' SIB would ever stop or improve. Themes of personal responsibility were common and many mothers felt that they should be helping their offspring overcome the behaviour, although they often felt unable to do so.

Although all the mothers made attributions about the locus of cause which were often contradictory, at some point each of them speculated that the cause was internal to their offspring and reflected an expression of their internal state or attempt to communicate something. The majority of those mothers who indicated a degree of self blame in causing their offsprings' SIB made reference to specific situations or behaviours. Despite the fact that the mothers made these types of attributions, a proportion of them expressed negative views about the utility of interventions suggested to them by professionals. This appeared to be because the rationale behind them contradicted their understanding of the problem, as suggested by recent

literature (Qureshi 1993; Hassall & Rose 2005). This is a significant point, as mothers are operating from a different frame of reference to detached professionals. Mothers are by definition emotionally involved and have difficulties with, for example, planned ignoring, when their child is distressed.

The most consistent finding from the qualitative analysis concerned attributions of stability. Many of the mothers were pessimistic about the possibility of sustained change and several held the view that their offsprings' SIB was chronic. Unsurprisingly, these views were associated with expressions of the grinding nature of dealing with the behaviour, or in fears for the future. These mothers may be at particular risk of depression with a consequent detrimental effect on the quality of interaction with their offspring, which may further affect their own quality of life (Greenberg, Seltzer & Greenley 1993). However, the hypothesised association between such attributions of stability and stress was not borne out by the quantitative analysis. This discrepancy between the qualitative and quantitative findings highlights the importance of exploring the meaning of the attributions and demonstrates the importance of having a qualitative component to exploratory attributional research.

Another finding of note concerning attributions of controllability again concerned the interventions used to deal with the SIB. A number of the mothers felt that although in the short term such interventions enabled their offspring to stop the behaviours, they were not having any lasting effect. The feeling was that these mothers were hopeful that there might be an improvement in their offsprings' behaviour but that there must be something more effective to try to help them achieve this. This has implications for engagement in interventions and stress. Hastings and Johnson (2001) have found that parents of autistic children who engage in an intervention and who believe that their offspring's condition can change experience less stress than more

pessimistic parents. The contextual effect of the SIB was apparent in this attributional dimension, in that a number of mothers felt more vulnerable when their offspring engaged in SIB in a more public forum, as suggested by Bandura (1989). This highlights the difficulties such families face when confronted with such behaviour and could lead to an increased feeling of stress (Qureshi 1990). This in turn could have a detrimental effect both on the quality of the relationship between parent and offspring, and lead to decreased opportunities for inclusion in the community.

Mothers also made attributions about controllability and expressed a range of views encompassing personal control of their offspring, their own personal control and more mixed attributions. The predicted association between mothers' attributions of their offsprings' personal control and their own parenting self-efficacy was not found. Instead, the association was in the opposite direction, with mothers who reported feeling that the behaviour was under their own personal control experiencing lower feelings of self-efficacy. The qualitative analyses suggest that these mothers felt burdened by their feelings of responsibility and, tied in with their pessimism about the possibility of change, felt that they were unable to help their offspring gain control of the behaviour and their methods for dealing with it were ineffective, especially in the longer term. The finding that some mothers who perceived themselves to have personal control were struggling with the responsibility of helping their child has implications for 'learned helplessness' theory (Abramson et al. 1978). Mothers may feel helpless if they feel they have control but perceive that they have too much responsibility to manage by themselves. Control was clearly linked to stress in the qualitative analyses; whether it be attempting to take control to reduce stress, feeling that control has been relinquished to the offspring in a more public context or the role of support in reducing stress. Many of the mothers expressed views about the quality of the support they received. It seemed that this was variable, with a number of mothers feeling that they had inadequate or even unhelpful support, which added

to their experience of stress. For those mothers whose experience was positive, generally there only one specific source of support was mentioned, whether that be a support group, member of a community learning disability team or friends and family. The contribution of support in helping to reduce stress has been clearly outlined (Hassall, Rose & McDonald 2005). It may be that self-efficacy is associated with the ability to strike a balance between retaining personal control and feeling that they receive adequate support for their role from those around them, whether it be formal or informal.

### **Implications for clinical practice**

The attributions made by mothers in this study are relevant to clinical practice. Although the numbers of mothers demonstrating particular patterns of attributions are small, the beliefs and experiences of the participants in this study may powerfully reflect those of the wider population of parents who have offspring with self-injurious behaviour. Clinicians involved with this population should be aware that mothers are likely to make attributions about their offsprings' self-injurious behaviour, which may impact on how they view interventions aimed at reducing the behaviour, their optimism regarding change and the amount of control they feel over it. As attributions are amenable to change (e.g. Coleman & Karraker 1997; Bugental & Johnston 2000; Wilson & Linville 1985), the early identification of attributions that may be problematic for parents and their offspring is important. This may involve working in a more systemic way and including all carers in the assessment and formulation process, and ensuring that all concerned parties accept the rationale for interventions, as advocated by Allen (1999). Acknowledging the attributions parents make will better able professionals to support families caring for offspring with self-injurious behaviour. Furthermore, recognising the need to support family carers in dealing with such behaviours and ensuring that they do not feel isolated or ignored and do feel 'listened to' would be beneficial in enhancing their well-being and

consequently that of their offspring. Social networks have been found to be associated with reduced stress levels in parents (Krauss 1993).

### **Implications for further research**

Despite the undoubted benefits of the mixed qualitative and quantitative methods used in this study, there were a number of limitations. In the first instance, using a convenience sample could lead to unknown biases. For example, a number of the participants in the sample were recruited through the family liaison officer of one organisation whose specific role was dealing with crises. Further studies should aim to compare larger samples obtained through a wider variety of sources to explore whether these affected the attributions that parents make. The number of participants was restricted by the time scale of the study, the recruitment difficulties outlined above and the labour intensive nature of the qualitative analyses, which further reduces the generalisability of the findings. A larger sample size would improve both the statistical power of the quantitative findings and would ensure theoretical saturation of the qualitative data. It may also allow more clear-cut groupings in terms of themes to emerge. The influence of such sample characteristics of age of the offspring, type and frequency of SIB could then also be examined. Furthermore, it would be interesting to explore the differences in experiences and attributions of mothers and father of offspring with self injurious behaviour.

A criterion of study quality such as participant validation could have been usefully employed. This involves returning the results of a study to the participants for comment to ensure that the account is recognisable and relevant to them and is analogous to 'internal validity' in conventional criteria (Elliot et al. 1999). Study participants' reactions to the analyses are then incorporated into the study findings. Some researchers view this as the strongest available check on the credibility of a

research project (Mays & Pope 2000). However, the geographical dispersal of the participants would have made it difficult to meet with them on a second occasion to obtain their perceptions of the results. Furthermore, one of the key study findings was the broad range of views expressed by the small group of participants. Given that this was the case, it might also be expected that they would hold very different views about the analyses, thereby making the value of the participant validation process questionable.

No comparison group was included in this study. It may have been interesting to compare the attributions made by mothers of offspring exhibiting SIB with those of mothers of offspring displaying other types of challenging behaviour. A measure of maternal depression might also have been usefully included in this study.

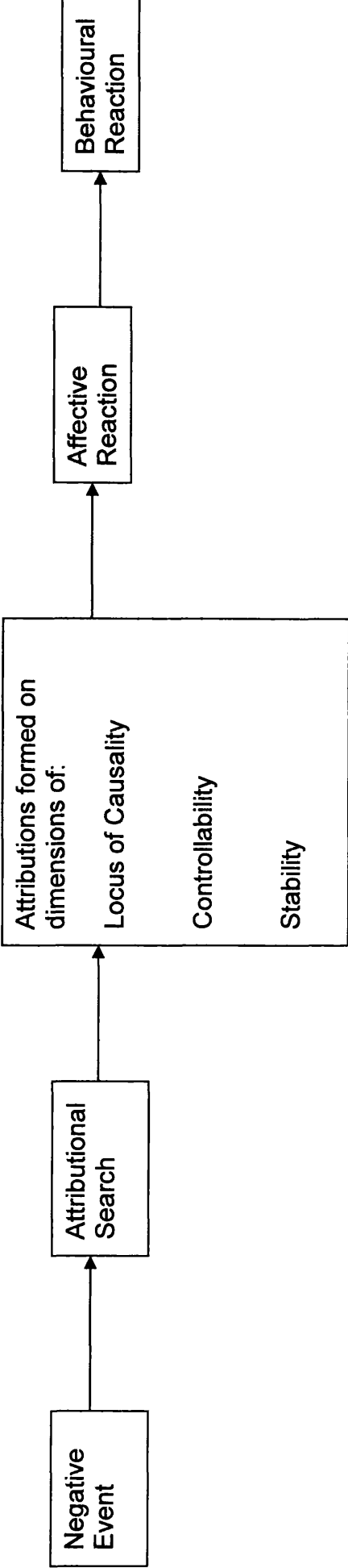
Mothers had no difficulties in spontaneously generating attributions linking to the dimensions of locus of cause, stability and controllability. These dimensions were meaningful for these mothers, however, they predate Weiner's (1980) model. In terms of the model, there are problems as there are no discrete categories and attributions do not follow a simple linear model. The model needs to be contextual, dynamic and linked to emotion. It is important for professionals to understand that there is not a simple conceptual relationship when working with these parents.

## **Conclusion**

The diversity of views expressed by these mothers reflects the complexities surrounding dealing with highly emotive and stressful events such as their offsprings' self injurious behaviour. The study demonstrated the relative relevance of attributional dimensions in understanding the views that mothers hold about their offsprings' SIB. The combined quantitative and qualitative methods allowed insight into the nature and types of attributions that mothers make and the implications of

these beliefs for both mothers and offspring. The context in which the behaviours occur has important implications, but does not appear to change the nature of attributions or necessarily affect stress or self-efficacy directly. It would seem that mothers feel that they are or are not effective. Furthermore, mothers seem to feel that they have all the responsibility but lack the control. The importance of appropriate support for family carers of these offspring is emphasised, along with the necessity for professionals to take account of the beliefs that mothers hold. Such an understanding may be helpful in engaging the parents in interventions aimed at reducing the behaviours, and in increasing their perception of control. This would have important implications both for the parents themselves and their offspring.

**Figure 1. A model of the attributional process based on Weiner (1980)**





**Table 1.** Criteria for selecting data from transcripts relating to locus of cause, stability & controllability

<b>Locus of cause</b>	
1	Attributes to internal causes/blames self
2	Attributes to mixture of causes/no clear element of blame of self/others
3	Attributes to external cause and clearly indicates blame
<b>Stability</b>	
1	Expresses view that SIB will stop/cause of SIB unpredictable/offspring doesn't need to change, just better understanding
2	Making some progress but will always be there/causes of SIB vary
3	Chronic, no change/hopeless about stopping/causes of SIB predictable
<i>Controllability</i>	
1	Offspring solely responsible for behaviour/parent sees self/outside agency as having no active role/behaviour outwith parent control
2	Responsibility equally shared between parent/outside agency and offspring for controlling behaviour
3	Parent or outside agency solely responsible for intervening/helping to stop/behaviour outwith offspring control

**Table 2.** Descriptive data from mothers' scores on the standardised measures (Parenting Self Efficacy Scale and Parenting Stress Index).

Measure (N=13)	Mean	SD	Range
Parenting Self Efficacy Scale	17.69	7.49	9 - 30
Parenting Stress Index			
Total stress	319.15	35.94	238 - 374
Parent domain	157.77	23.22	133 - 182
Child domain	161.38	26.54	105 - 195

**Table 3.** Spearman's rho correlations between the mothers' ratings on the attributional dimensions and their scores on the standardised measures.

	Attributional Dimension					
Measure	CAUSALITY N=13		STABILITY N=13		CONTROLLABILITY N=13	
	r=	Sig.	r=	Sig.	r=	Sig.
Parenting Self Efficacy Scale	-.264	.192	-.111	.358	-.586*	.018
Parenting Stress Index Total Score	.156	.306	-.056	.428	-.142	.321

\*significant at 0.05 level, 1 tailed

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## **Chapter 5**

### **Single-Case Experimental Design Abstract**

**The manipulation of arousal on the intensity of urges to pull hair in a 16 year old female with trichotillomania: A single-case experimental design.**

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[Prepared in accordance with guidelines for submission to *Behavioural and Cognitive Psychotherapy* (see Appendix 6.1)]

## **ABSTRACT**

Hairpulling (Trichotillomania) is often linked to stressful circumstances and may produce feelings of guilt, shame and humiliation. In a behavioural model of trichotillomania, affective experience was identified as an important maintaining factor, as both a cue and reinforcer. The present study evaluated the role of emotional arousal in the intensity of urges to pull hair in a teenaged patient with trichotillomania. Using an experimental ABCD/DCBA reversal design, the patient was assisted to engage in imagery aimed at increasing her emotional arousal through the presentation of a manipulation script based on her own experience, after baseline and during a rumination, cognitive and a behavioural distraction phase. Subjective measures of urge intensity were collected at 5 time points during completion of a task, and a tally was made of an overt hair touching behaviour operationalised as a hairpulling substitute behaviour. The patient experienced more intense urges to pull whilst ruminating on the arousal script when compared to either of the distraction phases. The findings support the view that the experience of negative emotional arousal can exacerbate and intensify the experience of urges to pull hair in patients with trichotillomania, and that both cognitive and behavioural distraction techniques have some effect in controlling them.

**Keywords:** Trichotillomania; arousal; distraction; single-case; cognitive; behavioural

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## APPENDIX 1.1      **Note for Contributors *Health Bulletin***

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- 1) All manuscripts must be submitted online at <http://bjp.edmgr.com> .

First-time users: click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

Registered users: click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

- 2) Follow the step-by-step instructions to submit your manuscript.
- 3) The submission must include the following as separate files:
  - o Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - Editorial Manager Title Page for Manuscript Submission
  - o Abstract

o Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - Editorial Manager - Tutorial for Authors

Authors can log on at any time to check the status of the manuscript.

## 5. Manuscript requirements

- \* Contributions must be typed in double spacing with wide margins and on only one side of each sheet. All sheets must be numbered.

- \* Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.

- \* Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.

- \* All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention and results or conclusions of the article.

- \* For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.

- \* SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.

- \* In normal circumstances, effect size should be incorporated.

- \* Authors are requested to avoid the use of sexist language.

- \* Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For Guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA (<http://www.apastyle.org> )

## 6. Publication ethics

Code of Conduct - Code of Conduct, Ethical Principles and Guidelines  
Principles of Publishing - Principle of Publishing

## 7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

## 8. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication.

## 9. Copyright



To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

10. Checklist of requirements:

- \* Abstract (100-200 words)
- \* Title page (include title, authors' names, affiliations, full contact details)
- \* Full article text (double-spaced with numbered pages and anonymised)
- \* References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs.
- \* Tables, figures, captions placed at the end of the article or attached as a separate file.

## **APPENDIX 2.2: Search Strategy for Systematic Literature Review**

### **Database searching**

1. OVID databases (MEDLINE, Embase, PsychINFO, CINAHL)

("Caregivers"/ or "Caregiver Burden"/ or "Stress"/ or Aging/ )

(parent\$ and "adult offspring" and (mental illness\$ or mental disorder\$ or learning difficult\$ or learning disorder\$) and (aging or stress or caregiver\$)).

2. CSA databases (ASSIA, ERIC, Social Services Abstracts, Sociological Abstracts)

KW=parent\* and KW=((mental illness\*) or (mental disease\*) or (learning disorder\*)) and KW=(stress or aging or (caregiver burden))

### **Reference searching**

The references of the included studies were inspected for further studies.

### **Hand-searching**

The following journals were hand-searched for the specified time period:

- a) *Psychiatric Services*
- b) *American Journal of Mental Retardation*
- c) *Family Relations*

## **APPENDIX 3.1      Course Guidelines for Major Research Project Proposals**

### **Major Research Project Proposal**

This can be written in the form of an application to a Local Research Ethics Committee and be presented, in full, in the final Research Portfolio. A copy of the letter(s) of ethical approval received from the LREC must also be included in the Research Portfolio. In circumstances where the completed project deviated from the original approved plan, the trainee must insert a clear explanation of these changes. Any further correspondence with the LREC, which relates to such changes must also be appended. The Major Research Project Proposal should include the following headings.

- Full title of project
- Summary of Project
- Introduction
- Aims and hypotheses
  - *Aims*
  - *Hypotheses*
- Plan of Investigation
  - *Participants*
  - *Recruitment*
  - *Measures*
  - *Design and Procedures*
  - *Settings and Equipment*
  - *Power Calculation*
  - *Data Analysis*
- Practical Applications
- Timescale
- Ethical Approval
- References

### **APPENDIX 3.2.      Format and topics of interest for the pilot focus group**

Participants will be informed that the purpose of the discussion is to explore their experiences of their offsprings' self-injurious behaviour in public and private and that it will be used to inform the main study. Consent for participation and recording of the discussion will be obtained, and that they can withdraw at any time. The format will be semi-structured and prompts will be provided for the following topics of interest:

#### *Reasons for SIB*

Along with general questions about why the SIB occurs, participants would be asked about the degree of control the person has over it, and whether it is due to internal or external factors. These questions are aimed at clarifying how 'understandable' the SIB is for the parent in different contexts, and whether they are concerned with an underlying meaning for the behaviour. This may have a bearing on how the parents interact with the person.

#### *Dealing with SIB*

Participants would be asked how they dealt with the behaviour and why, along with whether their initial impulse differed from what they actually did.

#### *Self-Efficacy Beliefs*

The participants would be questioned about how able to deal with the SIB they feel themselves to be in different contexts, and this may give further information about what affects these beliefs.

#### *Emotional Reactions*

These questions will explore what participants' feelings were in response to the SIB, and how they felt about the situation and the person in both public and private contexts. They will further be asked whether their emotions affected how they responded.

### *Stress*

Participants would be asked about the particular stresses of dealing with SIB in public and private, and how they cope with them.

Any other issues of relevance to the study will also be explored.

## **APPENDIX 4.1      Notes for Contributors to the *British Journal of Clinical Psychology***

### **Notes for Contributors**

The Editorial Board of the British Journal of Psychology is prepared to consider for publication:

- (a) reports of empirical studies likely to further our understanding of psychology;
- (b) critical reviews of the literature;
- (c) theoretical contributions.

Papers will be evaluated by the Editorial Board and referees in terms of scientific merit, readability, and interest to a general readership.

#### **1. Circulation**

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

#### **2. Length**

Papers should normally be no more than 8,000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

#### **3. Reviewing**

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

#### **4. Online submission process**

- 1) All manuscripts must be submitted online at <http://bjp.edmgr.com> .

First-time users: click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

Registered users: click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

- 2) Follow the step-by-step instructions to submit your manuscript.

- 3) The submission must include the following as separate files:

- o Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - Editorial Manager Title Page for Manuscript Submission

- o Abstract
  - o Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.
- 4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - Editorial Manager - Tutorial for Authors

Authors can log on at any time to check the status of the manuscript.

## 5. Manuscript requirements

- \* Contributions must be typed in double spacing with wide margins and on only one side of each sheet. All sheets must be numbered.
- \* Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- \* Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
- \* All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention and results or conclusions of the article.
- \* For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- \* SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- \* In normal circumstances, effect size should be incorporated.
- \* Authors are requested to avoid the use of sexist language.
- \* Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For Guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA (<http://www.apastyle.org> )

## 6. Publication ethics

Code of Conduct - Code of Conduct, Ethical Principles and Guidelines  
Principles of Publishing - Principle of Publishing

## 7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

## 8. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication.

## 9. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

## 10. Checklist of requirements:

- \* Abstract (100-200 words)
- \* Title page (include title, authors' names, affiliations, full contact details)
- \* Full article text (double-spaced with numbered pages and anonymised)
- \* References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs.
- \* Tables, figures, captions placed at the end of the article or attached as a separate file.



## APPENDIX 4.2 Ethical approval from Greater Glasgow

North Glasgow University Hospitals  
Division

### Glasgow Royal Infirmary LREC (2)

4th floor, Walton Building  
Glasgow Royal Infirmary  
84 Castle Street  
GLASGOW  
G4 0SF

Telephone: 0141 211 4020  
Facsimile: 0141 232 0752



26 August 2005

Dr Emma E Drysdale  
Trainee Clinical Psychologist  
Academic Centre  
Gartnavel Royal Hospital  
1055 Great Western Road Glasgow  
G12 0XH

Dear Dr Drysdale

**Full title of study:** An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.

**REC reference number:** 05/S0705/64

The Research Ethics Committee reviewed the above application at the meeting held on 19 August 2005. Thank you for attending the meeting along with Dr Jahoda and answering questions from the Committee.

#### Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Application		20 July 2005
Investigator CV		(None Specified)
Protocol		29 April 2005
Covering Letter		19 July 2005
Interview Schedules/Topic Guides	1	01 June 2005
Copy of Questionnaire	1	01 June 2005
Participant Information Sheet (Focus Group)	1	01 June 2005
Participant Information Sheet (Interviews)	1	01 June 2005
Participant Consent Form (Focus Group)	1	01 June 2005
Participant Consent Form (Interviews)	1	01 June 2005

#### Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.



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## Glasgow Royal Infirmary LREC (2)

## Attendance at Committee meeting on 19 August 2005

## Committee Members:

Name	Profession	Present?	Notes
Dr Malcolm Booth	Consultant in Anaesthesia & Intensive Care	Yes	Chair
Dr Miles Fisher	Consultant	Yes	
Mr Julian May	Lay member	Yes	
Miss Fiona Mackelvie	Lay member	Yes	
Mr Colin McKay	Senior Lecturer	No	
Mrs Fiona McMillan	Lead Pharmacist Clinical Governance	No	
Dr Anne Parker	Consultant	Yes	
Dr Fatwui Poon	Consultant Radiologist	No	
Mr Sandy Weatherhead	Lay member	No	
Ms Margaret McDonald	Lay member	Yes	
Mr Angus McFadyen	Statistician	No	
Mr Michael Bromby	Lay member	Yes	Co-opted from REC/1

## Also in attendance:

Name	Position (or reason for attending)
Mrs Sharon Macgregor	Administrative Officer

**Further information or clarification required****Participant Information Sheet - Focus group:**

1. Since the full title is not self-explanatory to a lay person, a simplified lay title should also be included.
2. The "What will happen if I take part?" section needs to be simplified to explain what a focus group is, how big is it and what happens.
3. In the "Possible Disadvantages?" section, the REC suggests replacing "self-injurious behaviours" with "self-harm". The word "self-efficacy" should also be explained in lay terms.
4. In the "Purpose of the study?" section, paragraph 3, the first sentence "improving parental well being etc" suggests parental blame. This sentence should be rewritten so that it is more positive.
5. As stated in the PIS Guidelines, contact names and telephone numbers should be inserted at end of Participant Information Sheet.

**Participant Information Sheet - Interview group:**

6. Comments 1, 3-5 above should also be applied to this sheet. References to the focus groups can be removed for simplicity.

**Consent forms:**

7. The lay titles that are to be added to the PISs should also be stated in the consent forms.

**Additional Documentation:**

8. A copy of the Parenting Stress Questionnaire should be submitted for our files.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates, along with a covering letter answering each point separately.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 24 December 2005.

**Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

**Communication with sponsor and care organisation(s)**

This communication is confidential but you may wish to forward copies to your sponsor and/or relevant NHS care organisation(s) for their information.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/S0705/64

Please quote this number on all correspondence

Yours sincerely



**Mrs Sharon Macgregor**  
**Administrator**

Email: [sharon.macgregor@northglasgow.scot.nhs.uk](mailto:sharon.macgregor@northglasgow.scot.nhs.uk)

Enclosure:

Attendance at Committee meeting on 19 August 2005



## APPENDIX 4.3 Ethical approval from Greater Glasgow

North Glasgow University Hospitals  
Division

### Glasgow Royal Infirmary LREC (2)

4th floor, Walton Building  
Glasgow Royal Infirmary  
84 Castle Street  
GLASGOW  
G4 0SF

Telephone: 0141 211 4020  
Facsimile: 0141 232 0752



13 October 2005

Dr Emma E Drysdale  
Trainee Clinical Psychologist  
Academic Centre  
Gartnavel Royal Hospital  
1055 Great Western Road Glasgow  
G12 0XH

Dear Dr Drysdale

**Full title of study:** An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.

**REC reference number:** 05/S0705/64

Thank you for your letter of 02 September 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

#### Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

#### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		20 July 2005
Investigator CV		
Protocol		29 April 2005



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Covering Letter		19 July 2005
Interview Schedules/Topic Guides	1	01 June 2005
Questionnaire	1	01 June 2005
Participant Information Sheet - Focus Groups	2	August 2005
Participant Information Sheet - Interviews	2	August 2005
Participant Consent Form - Focus Group	2	August 2005
Participant Consent Form - Interviews	2	August 2005
Response to Request for Further Information		02 September 2005
Parenting Stress Index Item Booklet		

#### Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

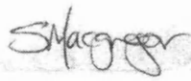
#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/S0705/64	Please quote this number on all correspondence
-------------	--

With the Committee's best wishes for the success of this project

Yours sincerely





Dr Malcolm Booth  
Chair

Email: sharon.macgregor@northglasgow.scot.nhs.uk

Enclosures:      *Standard approval conditions*  
                         *Site approval form*

Copy to:            R&D Office  
                         NHS Argyll & Clyde  
                         Top Floor, Ward 15  
                         Dykebar Hospital  
                         Grahamston Road  
                         Paisley  
                         PA2 7DE

SF1 list of approved sites

Glasgow Royal Infirmary LREC (2)					
LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION					
For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.					
REC reference number:	05/S0705/64	Issue number:	1	Date of issue:	13 October 2005
Chief Investigator:	Dr Emma E Drysdale				
Full title of study:	An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.				
This study was given a favourable ethical opinion by Glasgow Royal Infirmary LREC (2) on 07 October 2005. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.					
Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes <sup>(1)</sup>
Dr Emma Drysdale	Trainee Clinical Psychologist	Old Johnstone Clinic and Elizabeth Martin Clinic, Greenock	Argyll & Clyde Local Research Ethics Committee	13/10/2005	
Approved by the Chair on behalf of the REC:					
<div style="display: flex; justify-content: space-between;"> <div>             (delete as applicable)         </div> <div>           (Signature of Chair/Administrator)         </div> </div> <div style="display: flex; justify-content: space-between; margin-top: 10px;"> <div>             (Name)         </div> <div>           (Name)         </div> </div>					

(1) The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension or termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.



## Central Office for Research Ethics Committees (COREC)

### RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

#### Standard conditions of approval by Research Ethics Committees

1. Further communications with the Research Ethics Committee
  - 1.1 Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as "the Committee") are the personal responsibility of the Chief Investigator.
2. Commencement of the research
  - 2.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.
  - 2.2 In the case of research requiring site-specific assessment (SSA) the research may not commence at any site until the Committee has notified the Chief Investigator that the favourable ethical opinion is extended to the site.
  - 2.3 The research may not commence at any NHS site until the local Principal Investigator (PI) or research collaborator has obtained research governance approval from the relevant NHS care organisation.
  - 2.4 Should the research not commence within 12 months, the Chief Investigator should give a written explanation for the delay. It is open to the Committee to allow a further period of 12 months within which the research must commence.
  - 2.5 Should the research not commence within 24 months, the favourable opinion will be suspended and the application would need to be re-submitted for ethical review.
3. Duration of ethical approval
  - 3.1 The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.
4. Progress reports
  - 4.1 Research Ethics Committees are required to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief

SOPs version 3.0 dated June 2005

SL-AC2 Approval conditions (research other than CTIMP)



Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

- 4.2 Progress reports should be in the format prescribed by COREC and published on the website (see <http://www.corec.org.uk/applicants/apply/progress.htm>).

- 4.3 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

## 5. Amendments

- 5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

- 5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:

- (a) the safety or physical or mental integrity of the trial participants
- (b) the scientific value of the trial
- (c) the conduct or management of the trial.

- 5.3 Notices of amendment should be in the format prescribed by COREC and published on the website, and should be personally signed by the Chief Investigator.

- 5.4 A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

- 5.5 Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee.

## 6. Changes to sites (studies requiring site-specific assessment only)

- 6.1 Where it is proposed to include a new site in the research, there is no requirement to submit a notice of amendment form to the Committee. Part C of the application form together with the local Principal Investigator's CV should be submitted to the relevant LREC for site-specific assessment (SSA).

- 6.2 Similarly, where it is proposed to make important changes in the management of a site (in particular, the appointment of a new PI), a notice of amendment form is not required. A revised Part C for the site (together with the CV for the new PI if applicable) should be submitted to the relevant LREC for SSA.

- 6.3 The relevant LREC will notify the Committee whether there is any objection to the new site or Principal Investigator. The Committee will notify the Chief Investigator of its opinion within 35 days of receipt of the valid application for SSA.

- 6.4 For studies designated by the Committee as exempt from SSA, there is no requirement to notify the Committee of the inclusion of new sites.
7. Urgent safety measures
- 7.1 The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.
- 7.2 The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

## 8. Serious Adverse Events

- 8.1 A Serious Adverse Event (SAE) is an untoward occurrence that:
- (a) results in death
  - (b) is life-threatening
  - (c) requires hospitalisation or prolongation of existing hospitalisation
  - (d) results in persistent or significant disability or incapacity
  - (e) consists of a congenital anomaly or birth defect
  - (f) is otherwise considered medically significant by the investigator.
- 8.2 A SAE occurring to a research participant should be reported to the Committee where in the opinion of the Chief Investigator the event was related to administration of any of the research procedures, and was an unexpected occurrence.
- 8.3 Reports of SAEs should be provided to the Committee within 15 days of the Chief Investigator becoming aware of the event, in the format prescribed by COREC and published on the website.
- 8.4 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health or safety of research subjects.
- 8.5 Reports should not be sent to other RECs in the case of multi-site studies.
9. Conclusion or early termination of the research
- 9.1 The Chief Investigator should notify the Committee in writing that the research has ended within 90 days of its conclusion. The conclusion of the research is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.
- 9.2 If the research is terminated early, the Chief Investigator should notify the Committee within 15 days of the date of termination. An explanation of the reasons for early termination should be given.
- 9.3 Reports of conclusion or early termination should be submitted in the form prescribed by COREC and published on the website.

10. **Final report**
- 10.1 A summary of the final report on the research should be provided to the Committee within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the research including any feedback to participants.
11. **Review of ethical opinion**
- 11.1 The Committee may review its opinion at any time in the light of any relevant information it receives.
- 11.2 The Chief Investigator may at any time request that the Committee reviews its opinion, or seek advice from the Committee on any ethical issue relating to the research.
12. **Breach of approval conditions**
- 12.1 Failure to comply with these conditions may lead to suspension or termination of the favourable ethical opinion by the Committee.

North Glasgow University Hospitals  
Division

**Glasgow Royal Infirmary LREC (2)**

4th floor, Walton Building  
Glasgow Royal Infirmary  
84 Castle Street  
GLASGOW  
G4 0SF

Telephone: 0141 211 4020  
Facsimile: 0141 232 0752



19<sup>th</sup> December 2005

Dr Emma E Drysdale  
Trainee Clinical Psychologist  
Academic Centre  
Gartnavel Royal Hospital  
1055 Great Western Road Glasgow  
G12 0XH

Dear Dr Drysdale

**Full title of study:** An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.

**REC reference number:** 05/S0705/64

**Amendment number:** 1

**Amendment date:** November 2005

The above amendment was reviewed at the meeting of the Research Ethics Committee held on 16<sup>th</sup> December 2005

**Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**

The documents reviewed and approved at the meeting were:

*Protocol (Version 2, date November 2005)*

**Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

**Research governance approval**

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval of the research.



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**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/S0705/64

Please quote this number on all correspondence

Yours sincerely

*fr* 

**Mrs Rose Gallacher  
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**Enclosures** *List of names and professions of members who were present at the meeting and those who submitted written comments*

**Glasgow Royal Infirmary LREC (2)**

**Attendance at Committee meeting on 16 December 2005**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Malcolm Booth	Consultant in Anaesthesia & Intensive Care	Yes	
Dr Miles Fisher	Consultant	Yes	
Miss Fiona Mackelvie	Lay member	Yes	
Mr Julian May	Lay member	Yes	
Ms Margaret McDonald	Lay member	Yes	
Mr Colin McKay	Senior Lecturer	No	
Mr Angus McFadyen	Statistician	Yes	
Dr Anne Parker	Consultant	Yes	
Dr Fatwui Poon	Consultant Radiologist	Yes	
Mr Sandy Weatherhead	Lay member	Yes	
Mrs Kathleen Tuck		Yes	

**Also in attendance:**

<i>Name</i> Mrs Sharon Macgregor	<i>Position</i> Administrative Officer
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North Glasgow University Hospitals  
Division

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12 May 2006

Dr Emma E Drysdale  
Trainee Clinical Psychologist  
Academic Centre  
Gartnavel Royal Hospital  
1055 Great Western Road Glasgow  
G12 0XH

Dear Dr Drysdale

**Study title:** An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.

**REC reference:** 05/S0705/64

**Amendment number:** 2  
**Amendment date:** 21 April 2006

The above amendment was reviewed at a telephone meeting of a Sub-Committee of the REC held on 28 April 2006.

**Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	3	20 April 2006
Notice of Substantial Amendment (non-CTIMPs)	2	21 April 2006
Covering Letter		20 April 2006

**Membership of the Committee**

The members of the Ethics Committee who took part in the meeting are listed on the attached sheet.



01811

### Research governance approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval of the research.

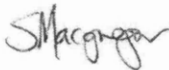
### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/S0705/64

Please quote this number on all correspondence

Yours sincerely



**Mrs Sharon Macgregor**  
Committee Co-ordinator

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Copy to: GRI R&D Department

Enclosures List of names and professions of members who were present at the meeting and those who submitted written comments



Glasgow Royal Infirmary LREC (2)

Attendance at Sub-Committee of the REC meeting on 28 April 2006

Committee Members:

Name	Profession	Present?	Notes
Dr Malcolm Booth	Consultant in Anaesthesia & Intensive Care	Yes	Chair
Dr Miles Fisher	Consultant	Yes	



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### **Participant Information Sheet – Interviews**

#### **What explanations do parents have for their child with intellectual disabilities' self-harm, and how do these relate to feelings of stress and competence?**

An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

#### **What is the purpose of the study?**

Research suggests that people try to make sense of upsetting or unexpected events. Parents whose children have behaved in a distressing way look for ways of explaining the behaviour to themselves. These explanations may affect their confidence in their own ability to deal with their child if they harm themselves, and the stress this causes. Family relations literature suggests that whether the child harms themselves in private or in public influences parents' explanations for the behaviour, as well as their feelings of competence as a parent.

You are invited to take part in an interview. The initial aim of the study is to look at parents' explanations for their child's self-harm. The study will then explore what this means for the parents, the effect on their confidence as parents and the stress they feel. The different effects on parents of self-harming that happens in public and in private will then be examined. This will be done through a combination of interviews and questionnaires. The research may suggest ways of reducing parents' stress levels and helping them feel more confident about their abilities to cope with the behaviour.

The study will run for 10 months.

**Why have I been invited to take part?**

You have been invited as the mother of an adult with learning disabilities whose behaviour can cause self-injury. At least 16 other mothers will also be invited to take part.

**Do I have to take part?**

No – it's your choice. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are still then free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your son or daughter receives.

**What will happen if I take part?**

You will meet with the researcher once for up to 2 hours. She will ask you about your experiences of your child's self-harming behaviour. This interview would be an opportunity to discuss your experiences in a supportive context. You will also be asked to fill in two questionnaires: one about your confidence as a parent and the other about the amount of stress you experience. The interview will take place in a setting in which you feel comfortable, either in your own home or perhaps the offices of the Community Learning Disability Team. It will be recorded and transcribed, but anonymised so that you cannot be identified.

**What are the possible disadvantages of taking part?**

You may find talking about your child's behaviour distressing. However you may find the interview helpful in airing your feelings. Every effort will be made by the researcher to ensure you don't become unduly distressed. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

**What are the possible benefits of taking part?**

There will be no direct advantage to you personally in taking part. However, we hope that this research will identify approaches that would help both parents and individuals with intellectual disability who harm themselves in the future.

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the building will have your name and address removed so that you cannot be recognised from it. Recordings and transcripts will be kept securely and eventually destroyed.

**What will happen to the results of the study?**

We expect that the results will be published in a research journal. However, you will not be identified.

**Who has reviewed the study?**

The research has been reviewed and passed by the University of Glasgow and the Glasgow Royal Infirmary Research Ethics Committee.

**Contact for further information**

If you have any questions about the study or require further information before making a decision about taking part, please contact:

**Emma Drysdale**  
**Trainee Clinical Psychologist**  
**Academic Centre**  
**Gartnavel Royal Hospital**  
**1055 Great Western Road**  
**Glasgow G12 0XH**  
**0141 211 0607**

You will be given a copy of this information sheet and a signed copy of the consent form to keep.

Thank you very much for your participation.

August 2005 v.2



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## CONSENT FORM INTERVIEWS

**Title of Project:**

**What explanations do parents have for their child with intellectual disabilities' self-harm, and how do these relate to feelings of stress and competence?**

An investigation into the nature and content of spontaneous attributions and their relationship to feelings of self-efficacy and stress in parents of individuals with intellectual disabilities who exhibit self-injurious behaviour.

**Name of Researcher:**

Emma Drysdale

**Please  
initial box**

1. I confirm that I have read and understand the information sheet dated .....  
(version .....) for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw  
at any time, without giving any reason, without my medical care or legal

rights being affected.

☐

3. I agree to take part in the above study.

☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 for participant; 1 for research

**How confident are you in dealing with the self-injurious behaviour of your offspring?**

1	2	3	4	5	6	7
Not at all confident					Very confident	

**How difficult do you personally find it to deal with the self-injurious behaviour of your offspring?**

1	2	3	4	5	6	7
Very difficult					Not at all difficult	

**To what extent do you feel that the way you deal with the self-injurious behaviour of your offspring has a positive effect?**

1	2	3	4	5	6	7
Has no positive effect at all					Has a very positive effect	

**How satisfied are you with the way in which you deal with the self-injurious behaviour of your offspring?**

1	2	3	4	5	6	7
Not satisfied at all					Very satisfied	

**To what extent do you feel in control of the self-injurious behaviour of your offspring?**

1	2	3	4	5	6	7
Not in control at all					Very much in control	

## APPENDIX 4.9.      Derivation of Interview Schedule

The pilot phase of the study took the form of two individual unstructured interviews (equivalent to guided everyday conversation) with a couple of topic areas that were probed when opportunity arose, as per the technique outlined in Miller and Crabtree (1992). These topic areas were derived from the literature and included emotional reactions to self-injurious behaviour (SIB), self-efficacy beliefs and reasons for self-injurious behaviour. All of these topic areas were further probed for differences between public and private contexts. These broad a priori categories allowed for an open interview, in which examples of the categories could be observed to come up and also was sufficiently flexible to allow for new topics to be included.

These interviews resulted in a large volume of verbal text that then needed to be analysed. The form of analysis decided upon in order to derive a relevant semi-structured interview schedule was basic content analysis (Weber 1985, cited in Miller & Crabtree 1992). Transcripts of the interviews were searched for a priori categories based on the topic areas described above, frequency determining whether they were to be included in the schedule.

In developing the schedule, the aim was to capture a number of broad categories of information around several initial topics of interest derived from the literature. These included reasons for SIB, dealing with SIB, emotional reactions to SIB, self-efficacy beliefs and stress. On reading the transcripts, one further category became evident, that of supports. The advantages of using such a broad approach, as outlined by Crabtree and Miller (1992), to code the text and then count the frequency of different occurrences as a means of identifying key areas are that large amounts of text can be coded rapidly. Furthermore, coded segments of text that are longer preserve broader context.

The codings consisted of:

### *Reasons for SIB*

Statements about why the SIB occurs, degree of control the person has over it due to internal or external factors. Differences in public or private contexts.

Instances: Pilot 1 12 (3 about context)                      Pilot 2 8 (2 about context)

e.g. "sometimes if he's in pain or frustrated or annoyed or he's having to go somewhere he doesn't want to go, or if he's out with carers and like everybody, he

doesn't like every carer that he's got, so he's 'no go, no go , no go' and he's (demonstrates) starts again".

### *Dealing with SIB*

Statements about how they dealt with the behaviour and why.

Instances: Pilot 1 9 (3 about context)                      Pilot 2 5 (1 about context)

E.g. "At first, you're 'stop that', you know, and you get to the stage where he's not going to, so you try to hold his hands down but the problem with that is you get hurt doing that ... you go 'don't' and he'll say 'don't do that, B, don't do it' and as he says it he's banging himself. "

### *Self-Efficacy Beliefs*

Statements about how able to deal with the SIB they feel themselves to be, also in different contexts.

Instances: Pilot 1 5 (3 about context)                      Pilot 2 8 (1 about context)

E.g. "You feel helpless because he's a big man now and it's not like with little kids having a temper tantrum, you can say 'get to your bed' or 'stop that'. I mean we tried things, we tried mittens, like those ones, to take the force from it but he just bit through the string".

### *Emotional Reactions*

Statements about feelings in response to the SIB, and how they felt about the situation and the person in both public and private contexts.

Instances: Pilot 1 14 (5 about context)                      Pilot 2 15 (6 about context)

E.g. "It can be a very cruel world, as you know, at times. And people can be cruel, they just don't understand. It gets now, when we go out and he starts, he sits in the car with his music, he doesn't want to go round the shops with me. And I feel terrible, because I feel he's shut away".

### *Stress*

Statements about the particular stresses of dealing with SIB, in either public or private.

Instances: Pilot 1 10 (5 about context)                      Pilot 2 10 (5 about context)

E.g. "I think the most stressful thing is because he's so upset and uptight and I don't know why, and there's sometimes I don't know why, I find that most stressful, because you wonder is he in pain, because he would suffer pain and never tell you, or is it something that's happened and he's not telling you, you know, you get



frustrated and ask 'why are you doing that? Why are you biting your hands'? You get to yourself, you say, I wish I could understand more, deep down, what is really wrong?"

### *Supports*

An additional category that emerged from the transcripts, relating to statements about either formal or family supports and stress/coping with SIB.

Instances: Pilot 1 2                      Pilot 2 6

E.g. "When I've got him at home of an evening, he's ok if he's been with the two that he likes, that are good with him. It's like anything, some of them are good with him some of them are not, but that can absolutely kick you back in the face because he can have an absolutely fabulous shift when two of the worst workers are in. It just depends on how things have been. If they're late, like if they say they're stuck in traffic, it definitely puts a lot of pressure on me."

The protocol for the interview schedule was to be as open and discursive as possible without being leading. As can be seen from the schedule itself, each category was arranged to begin in an open fashion to start the conversation and then more specific probes were used to prompt for specific information if it did not come up spontaneously. The categories were used as a topic guide in a flexible fashion, in a natural and conversational manner, rather than as a fixed schedule. For example, the categories themselves may not make sense being separated to interviewees, but in laying them out in this way, this ensures that they are covered. Not all the prompts needed to be used as they may be covered in the general conversation.

For coding the text, distinction was made between categories spontaneously occurring before being probed and those occurring after prompts.

## REFERENCES

Crabtree, B. F. & Miller, W. L. (1992). *Doing Qualitative Research*. Newbury Park, CA: SAGE.

Crabtree, B. F. & Miller, W. L. (1992). A template approach to text analysis: Developing and using textbooks. In B.F.Crabtree & W. L. Miller (Eds.), *Doing Qualitative Research* (pp. 93-110). Newbury Park, CA: Sage.

Miller, W. L. & Crabtree, B. F. (1992). Depth interviewing: The long interview approach. In M.Stewart, F. Tudiver, M. Bass, E. Dunn, & P. Norton (Eds.), *Tools for primary care research* (pp. 194-208). Newbury Park, CA.: Sage.

Weber, M. (1985). *Basic content analysis*. Beverly Hills, CA.: Sage.

## **Semi-Structured Interview Schedule**

### *Definitions*

What do you understand by the term 'self-harming' or 'self-injury'?

What term do you personally use for your child's behaviour?

What behaviours does this include?

Discussion to ensure common understanding

### *Reasons for self-harm*

What do you think the reasons are that your son/daughter injures him/herself?

Have you thought of any other reasons?

Do you think (name) has any control over the self-harm?

Have you ever thought (name) does it 'on purpose'?

What sorts of things do you think might make it more likely to happen?

What kinds of things might be happening with (name) that make it more likely to happen, like if s/he's in a bad mood or not feeling well?

Have you ever thought it's anything to do with you, of anything you do that makes a difference?

Do you think it's different if it happens at home or when you're out and about?

### *Dealing with self-harm*

How do you deal with the self-injury?

What's brought you to dealing with it in this way?

Do you handle it differently when it happens in public than in private?

Can you tell me what some of the reasons for that are?

Does what your initial instinct about what to do differ from what you actually do?

If so, how?

### *Self-efficacy beliefs*

Thinking about what you do, how does it make you feel?

Does it always work?

How do you feel when it doesn't work?

When you're out and about, how do you feel then?

Is that different to when you're at home?

### *Emotional reactions*

How does it make you feel when (name) injures him/herself?

How do you feel about (name)?

What is it that makes you feel this way?

Does how you feel change depending on whether you're at home or out and about?

How do you feel about the situation?

### *Stress*

A lot of people find dealing with self-harm particularly stressful. What do you find the most stressful thing about dealing with (name's) self-harming behaviour generally?

How about in private?

And in public?

What do you find helps, what works for you?

### *Supports*

Who have you found gives you the most help out of everybody?

*If mention family/friends:* Do you find any professional support helpful?

*If mention professionals:* What about family and friends, do you find support from them helpful?

**APPENDIX 4.10. Full table of codings on attributional dimensions from transcript data and illustrative examples.**

<i>Attributional dimension</i>	<b>LOCUS OF CAUSALITY</b>		
<i>Mothers' ratings</i>	<p><b>Attributes to internal causes/blames self</b> n = 7 (initial) 13 (subsequent)</p> <p>Because I know that it's something that's totally attention seeking, he does it for effect. He does a lot of it to see who's watching it just seems to me, to me anyway, that it's something that I'm not doing that I should be doing or something I'm doing that I'm not supposed to be doing... And that's so annoying to think, if she could just tell me what it is then, that makes her angry about me, then I'll change it</p>	<p><b>Attributes to mixture of causes/no clear element of blame of self/others</b> n = 6 (initial) 8 (subsequent)</p> <p>And in my opinion, it might be because of a lack of communication, it might be a boredom thing, it might be frustration, it might be because she's upset or sad. Got a period, who knows. We haven't actually come up with any hard and fast reasons for why it might be, I'm sure there are lots and lots of reasons, it might be because there's not enough going on in her head, I don't know</p> <p>To me, self injury, I think there's multi factors. I think there's definitely, what was it the doctor said, "his brain's completely compromised". You know. There is that, I do believe that there is physiological cause. I think there's other factors, there is times when he does it, it's for communication, when he's frustrated, when he doesn't want to do something, if he doesn't want to be moved</p>	<p><b>Attributes to external cause and clearly indicates blame</b> n = 1 (initial) 9 (subsequent)</p> <p>He loves music, but he can't stand the tinny music of the shows. Er, that, oh, really agitates him. And babies crying, that starts him, he can't stand that. If we're out anywhere, you've got to get him away</p> <p>But actually taking him shopping, the crowds, he can't stand a lot of crowds. It seems to get him uptight a wee bit. It's awful difficult</p>

Attributional dimension	STABILITY		
<p><i>Mothers' ratings</i></p>	<p><b>Expresses view that SIB will stop/cause of SIB unpredictable/offspring doesn't need to change, just better understanding</b> n = 1 (initial) 3 (subsequent)</p> <p>I've learned to get to know [offspring] better, and other people, so I've had to change too, and other people are learning, how to get to understand [offspring] rather than trying to get him to change. Because of these things and that his health has improved, that's made a big difference to his self injury... which all helps him to cope with his behaviour and helps him not self injure.</p> <p>I think hopefully, that he'll stop, as he gets older and is able to understand more and catches up, not that he'll ever fully catch up but, you know, develops more, he'll have more understanding of what is right and wrong, and that he can't get everything that he wants</p>	<p><b>Making some progress but will always be there/causes of SIB vary</b> n = 5 (initial) 3 (subsequent)</p> <p>I get very upset for him if I go and he's got bad scratches in the morning. . .he can all of a sudden stop doing this for a while, for months and months not do it and then start up again.... I thought he'd outgrown it really</p> <p>She has kind of eased off a wee bit and there's lots of marks and things on her hand where she's done it and scabs and it's unpleasant and it must be sore. Yes, so, we all try, and that's really all we can do, move her hand away and keep doing it and hopefully she'll stop</p>	<p><b>Chronic, no change/hopeless about stopping/causes of SIB predictable</b> n = 7 (initial) 3 (subsequent)</p> <p>I think because loving your child with disabilities and with self harming tendencies is almost like a life sentence. I mean there's that thread that goes through your entire life, knowing that that's the way it's going to be</p> <p>I just try my best for him and cope with it the best I can, er, I don't think it'll ever be any different, I don't think there's anything more I can do. Even the psychologists and that have said that, you know, I mean, they know him so well now, there's nothing more that they can do</p> <p>If you give him a row, give him into trouble for something, he always does it. Always</p>

CONTROLLABILITY			
Attributional dimension	Offspring solely responsible for behaviour/parent sees self/outside agency as having no active role/behaviour outwith parent control n = 3 (initial) 10 (subsequent)	Responsibility equally shared between parent/outside agency and offspring for controlling behaviour n = 3 (initial) 6(subsequent)	Parent or outside agency solely responsible for intervening/helping to stop/behaviour outwith offspring control n = 8 (initial) 13 (subsequent)
Mothers' ratings	<p>he'll still self injure a bit but he'll stop it now, and he thinks about it now, he's even thinking about it now whereas in the past he'd went ahead and done it</p> <p>she does do half of it to wind me up, because she doesn't do it as much when her dad's here. But the minute he's away to work and I've got her till she goes out, she starts all morning ...I end up giving in to her. I think she plays up a lot to me and she knows I give it her in the end up</p> <p>.It's just such a physical feeling of sickness and just, you know, helplessness. As a mother, you're supposed to protect your child, and yet you're in a situation where you can only do your best and it's not going to be anywhere near good enough, it's not going to help. There's nothing I can do, I can't touch something or say something, that will make it better, and as a parent, that's what you want to be able to do. And I think that's it's a horrible feeling of lack of control</p>	<p>I've been told to try and ignore it which I can do for a wee while then it drives me absolutely bonkers and I need to go up and tell him to stop it or try and divert, 'come on we'll do this, come on we'll do that'. Sometimes that works and sometimes it doesn't. And it depends on the mood he's in, it depends on what I've come up with to try and divert him, if it's diverting enough for him. I find very much it's all his grounds, if you know what I mean.</p> <p>I think that fact that we've tried to stop her from doing it has helped her to stop it so that obviously that's not so unconscious</p>	<p>All I can do is distract him when I'm changing him and things. I'll take his hand away and go like that to him (demonstrates) and I'll say "only babies do that [offspring], big boys don't do that, only babies do that" and I take his hand away and he gives a big grin and the only thing I can do is stop him while I'm there.</p> <p>I take his hands away from his mouth. And I distract him maybe with something in the shops, or something that's maybe relating to him. I deal with it that way when I'm out, I don't make a big issue of it, you know. Because I think that the more you make an issue of it, the more you make it worse.</p>

**APPENDIX 4.11. Full table of implications of attributions relating to each dimension from transcript data**

LOCUS OF CAUSE			
Attributional dimension	Search for meaning and need to 'fix it' n = 9	Unhelpful public attitudes n = 4	Problems with acceptability of interventions n = 6
Implications of 'mothers' attributions	<p>if you feel frustrated, you get angry, you know, but it's the only way I can explain it really. And what the reason is, I don't know, or how to help him, I don't know. . . I just wish I had a thing for these hands.</p> <p>powerless, you feel as a parent that you should be able to help your child, and to help your child overcome any upsets that they have and sometimes you feel as if you're a tiny, tiny speck, unable to make the slightest bit of difference.</p> <p>Depending how he was, and other times, scream at him, "why are you doing this?" Being quite abusive to him, probably, saying things I regretted. But, on the other hand it was things you'd do with anybody that was driving you nuts. And you're trying your best to be good to him. But that was in the past. What I do now is er I talk to him, I say "you know I love you, show me how to help you", get a tablet, a drink, I tighten his splint up a bit to show I know that there's something wrong, I suggest things to him, go to bed, things like that, giving him options.</p>	<p>he's always looking for an audience and people'll come and try and help and then that's exactly what he's getting and it escalates then. It can make you hostile towards people, you tell them to just go away, to just leave me. The more people that's there, the more it'll go on.</p> <p>because you're out in the big world and everyone's watching you. Not that I give a hoot about what anybody thinks. . . But I think about [offspring] and his behaviour and other people get upset. People come over and say, "can I help you?" or things like that, and it's a nuisance, but it's people being nice, so I feel in a way that it's a bigger burden because I'm trying to deal with people and [offspring], and then that starts getting me a bit upset</p> <p>sometimes you get new carers that doesn't know him – "oh, how did [offspring] get these scratches?" and I feel I'm under scrutiny and that doesn't make me feel very good at all, as if I'd ever, could do anything like that to [offspring]</p>	<p>For me, I just see the self injury, I never felt the feeling that he's doing it for attention, it was more to do with how he was feeling and how he was reacting and ignoring it just, he could do so much damage I just felt I couldn't.</p> <p>when I was told to ignore it, and then you can't ignore it because you'd just be letting him carry on hurting himself, so in cases like that I can't take the advice</p>



STABILITY						
Attributional dimension	Implications of mothers' attributions	Negative emotion due to constant nature n = 11	Vulnerability in public n = 7	Stress of unpredictability n = 3	Fears for future n = 5	Interventions effective in short term only n=6
		<p>Really frustrated, sometimes I just ..hate him and other times I feel really sorry for him because he really hurts himself. And there's no reason for him to get into these states because he gets everything he ever needs, do you know. And at other times....you can bend over backwards and give him the sun and the moon and you've still to reach for the stars</p> <p>Sometimes I just feel that I could walk out the door and not come back; sometimes it makes you feel upset that you can't help your child to deal with it. And sometimes it just makes you feel angry. I suppose it depends what sort of day you're having yourself. (pause) I can't say it ever makes me feel calm.</p>	<p>you're in that situation outside, you're much more vulnerable, obviously, because you don't know what he's going to do. And if he's slapping himself and someone's passing, he's in control when you're out there. They could get the police involved, anything</p> <p>I take [offspring] to the pictures occasionally, and he's maybe starting, and I go to take him out, and as I'm leaving, someone's shouting "mum, what's he doing that for?" All these things. You only hear [offspring], you don't hear all the other kids, even though they're all doing it. You still feel that way, you're a nuisance. You don't feel your contributing to society. You don't. And you don't feel anybody else is making you feel you are</p>	<p>I start crying, you know. I need somebody here, even when he's having a good day, because you don't know, it's that unpredictable. You don't know if he's going to start hurting himself and the moment he does, there's the churning in my stomach, because of that feeling that you can't stop it</p> <p>people might be thinking 'why are you not doing anything about that?'. He can do it anywhere, the middle of the Bank of Scotland, or McDonalds, or a café or a coffee shop. He'll start and everybody wherever he is looks. I'm sat there trying to ignore him and everyone else is looking. So on days where he's a bit dodgy, you don't take him. It doesn't always work, you think he's ok and he goes</p>	<p>I don't know what to do with her, for it to work. Should I try and find out what's happening about a placement? That worries me and all, because I've had her all this time and you feel like you're just palming her off to somebody else</p> <p>unsure, and in what ways you could be helping him because you don't know what's for the best, you know. Er, there's not any centres as such as you would say, for parents, you know, to find out how they cope with different things. I often wonder if anything happened to myself and my husband, what would happen to him. My daughter says I've not to worry, but you can't put the burden.....on your family</p>	<p>[intervention normally works] as I said, if I take his hand away, but it'll only work while I'm there to stop him</p> <p>You just think, "I'm getting nowhere here". I can't help him get himself back into control. So I think that's the worst thing, not being able to help him to stop it. It might just be something he's got to work through. But you can't stand back. So you're back to, your stress levels go way up and helplessness, you just think what can I do for this child to stop him from doing this.</p>

CONTROLLABILITY					
Attributional dimension	Unhelpful nature of support n = 6	Negative views of offspring n = 5	Context – control n = 8	Positive experience of support n = 6	Taking control relieves stress n = 2
Implications of mothers' attributions	<p>When [offspring]'s bad, the level of support is rubbish because they only want to be there when he's good. When things are bad they run away. He has care from half one till five, and sometimes they go at quarter to two. 'Do you want us to sit here with him?' I just say 'go'. If they can't sustain 20 minutes, they're no use to me sitting there. If I deal with it myself and anybody gets hurt, it's only going to be me. Nobody else. So I feel that easier</p> <p>I got really depressed and suicidal and decided to end it and then I got social work involved and got some respite. But that was worse at first as it was residential respite and they couldn't look after the 2 boys at all. They'd come back worse than they went... I was getting phonecalls at 2 in the morning. I couldn't cope, I started thinking "what if something happens to me?" and I did get ill.</p>	<p>Sometimes, sometimes you really do hate your child (pause) and sometimes you really do wish your child was dead. I know that's a horrible thing to say but I know I'm sure that other parents of disabled children do feel that. And then that makes you feel guilty because it's your child and you've given birth to him and you do love him. No matter what he does he's your son and you do love him but sometimes you just can't go far enough</p> <p>she's a constant source of, er (pause) joy. But, frustration and difficulty, I suppose, pain really, anxiety definitely. And sadness. But you have to learn to live with that. If you allow that, you weren't able to cope with it for the rest of your life, you wouldn't be able to cope with anything really. You wouldn't be able to look after other kids, you wouldn't be able to have a relationship if you allow that to kind of get on top of you. So you have to manage</p>	<p>You just don't want to escalate things. So you are very very vulnerable outside. I'd much rather be in with him but if ...the care team take him out, I can't relax, I'm very aware they're going to be on the phone or bringing him back or whatever. So when we're in here, I'm in control; when we're outside, he's in control. I mean, I'm in control of what we're doing or whatever, and he's making it either comfortable or uncomfortable</p> <p>you're much more uncomfortable outside... in the house there are, you're less concerned about what other people are thinking. Much more, although you don't like to think that way, you don't like other people feeling embarrassed or uncomfortable or looking. And you really don't want to draw attention to the fact that she has a wide range of disabilities and does things that look abnormal outside... You confine it to your home so that we can (pause) contain her, sometimes I suppose. That's what it comes down to, you can contain her</p>	<p>they work very, very hard, the staff are very, very caring. It helps me, as I say, I don't know that I could have [offspring] there if I didn't know the staff. You know, to me, that takes the stress away. And especially the staff I know really well, who I know know [offspring] really, really well</p> <p>the respite where [offspring] goes away is great... when you've got a child like [offspring] you don't actually feel like you're normal either, because you don't get to do the normal things that other people do and take for granted... The people that come to the house are great because it means I can go to work. And I can have a relatively normal working life, because I have to work, I've always had to work full time, I've always been the breadwinner</p>	<p>if I can calm her down, if I can stop her from being miserable, then it's easy. If she's calm, I'm calm. If she's not calm, then I tend not to be. I can be, but sometimes it's difficult to maintain tranquillity in the face of difficult behaviour</p> <p>I don't mean that no one can do it as well as me, that's not what I mean. I'm soft with him, very soft, and I let him away with murder but....it's your life, you teeter along on the edge of it and you hope that one day is better than another</p>